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Modelling the interplay between childhood adversity, recent stressful life events and perceived social support in pathways to an 'ultra-high risk' (UHR) of developing psychosis

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Systematic Literature Review, Empirical Study and Service Evaluation

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Thesis submitted in partial fulfilment of the degree of Doctorate in Clinical
Psychology

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Dedication

For my mother, Dagmar Kalu (geb. Hauptmann).

*Danke fuer die Liebe and Unterstuetzung die Du mir in den ersten 17 Jahren meines Lebens
gegeben hast, und die fuer ein ganzes Leben ausreichen werden.*

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Contents

Systematic Literature Review:	The protective effects of social support at the onset of psychosis: a systematic review	5
Empirical Study:	Modelling the interplay between childhood adversity, recent stressful life events and perceived social support in pathways to an 'ultra-high risk' (UHR) of developing psychosis	56
Service Evaluation:	An audit of the assessment process in a National and Specialist CAMHS service and the development of a compulsory assessment package for clinical use	179

Systematic Literature Review:

The protective effects of social support at the onset
of psychosis: a systematic review

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Abstract

Background. There is strong evidence that supportive social relationships are associated with positive outcome variables in individuals with a long-standing psychotic disorder. Furthermore, evidence suggests that the social relationship deficits characteristic of psychosis are already apparent in the very early stages of the disorder. However, so far no comprehensive answer has emerged to the question of whether supportive social relationships have similar positive effects at psychosis onset, and which qualitative and functional aspects of support are attributed to these effects. A systematic review of the literature was therefore conducted to establish what is currently known about the relationship between perceived social support and outcomes in early psychosis.

Method. Medline, Embase and PyschINFO were searched for studies investigating perceived social support in 'ultra-high risk' (UHR) and first episode psychosis samples using the expressions ('schizophreni*' or 'psychosis' or 'psychotic disorder') and ('first episode') and ('ultra high risk' or 'UHR' or 'clinical high risk' or 'at risk mental state' or 'ARMS') and ('social support'). Findings were synthesised using non-quantitative approaches.

Results. A total of 3006 citations were screened and 11 studies were identified that met inclusion criteria. There was marked methodological heterogeneity, which limits the capacity to draw direct comparisons between the studies. Nonetheless, the existing literature suggests perceived social support has protective effects on service user outcome. These effects may be a function of support from friends and confidantes rather than from family members, and emotional support may be more important than practical support.

Conclusion. Perceived social support appears to have beneficial effects on symptom severity, functioning, and levels of remission and quality of life in early psychosis. There is a need for more robust and comparable studies that employ valid and reliable measures of perceived social support and its multidimensional domains to evaluate the effects further and determine the specific mechanisms responsible for these effects. Future studies should also address possible mediating and moderating effects of perceived social support on known risk factors for psychosis.

Table of Contents

Introduction	10
Social networks	10
Social support.....	11
Schizophrenia and psychosis.....	12
Conceptualisation, epidemiology and comorbidity	12
Early Psychosis and Ultra-High Risk (UHR) status	12
Social networks and social support in psychosis	13
Early research on social networks and support in psychosis.....	13
Recent studies on social network and support in psychosis	14
Aim of the current review	16
 Method	 17
Data sources.....	17
Study selection	17
Data extraction and synthesis.....	18
Quality assessment	18
 Results	 19
Quality Assessment.....	23
Beneficial effects on clinical features	24
Beneficial effects on QoL	27
Is there variation by the type of support provided.....	27
 Discussion	 28
Social support and symptom severity.....	28
Social support and functioning	29
Social support and remission	30
Understanding the pathways.....	30
Methodological consideration.....	32
Recommendations for future research.....	34

Conclusion	36
References	37
Appendices	48
Appendix 1: The EPHPP Quality Assessment Tool	48
Appendix 2: The EPHPP Quality Assessment Tool User Manual	52

List of Figures and Tables

Figure 1 PRISMA Diagram of selected studies	20
Table 1 Overview of studies included in the review	21
Table 1 Overview of studies included in the review cont.....	22
Table 2 Quality assessment results of studies included in this review	24

Introduction

The importance of social relationships for health has long been recognized (e.g. Cohen & Willis, 1985; Thoits, 2011). Individuals with good social relationships and social support tend to be physically and mentally healthier and live longer (Holt-Lunstand, Birmingham, & Jones, 2008). Conversely, those with low social support and dysfunctional social networks often have poorer physical and mental health, and poorer treatment outcomes (Greenblatt, Becerra et al, 1982). Over the past four decades researchers have tried to define and describe the quantitative and qualitative characteristics of social networks and social support that appear to contribute to these protective factors.

Social networks

Social networks (or social relationships) are a subset of the totality of social contacts (Greenblatt et al, 1982). They are defined by persistence over time and a degree of significance, and are considered to play an important role in the maintenance of the psychological and physical integrity of a person. Primary relationships (i.e. people who we primarily interact with and have commitments to, such as family members and friends) are distinguished from less personal secondary relationships (i.e. less personal or formal relationships, for example with teachers or with healthcare professionals) (Cresswell et al, 1992).

Social networks can be specified further in terms of structural and functional aspects. Functional aspects refer to what is provided by, or perceived to be available from social relationships, whereas structural aspects refer to the existence and pattern of interactions of network members rather than the content or quality of relationships (Hammer, 1981).

Social networks can also be described in terms of quantitative and qualitative aspects. Quantitative aspects include density and size of the network, kin vs. non-kin composition, marital status and living alone vs. living with others (Lundgard, 2007). Qualitative aspects refer to an individual's degree of satisfaction with their social relationships. This includes reciprocity (the extent to which the relationship is

characterized by giving as well as receiving), accessibility (the ease with which network members can be contacted), multiplexity (the number of separate functions provided by relationships), social isolation (pervasive lack of social contact or communication), the presence or absence of a confidant (someone who provides a relationship characterized by emotional intensity, reciprocity and availability), and loneliness (i.e. a discrepancy between the actual relationships one perceives to have and the relationships one desires) (Peplau & Perlman, 1982; Lundgard, 2007).

Social support

Social networks are important because they are the vehicle for delivering social support. Social support can be received from both primary relationships (e.g. family support, support from friends or significant others) and secondary relationships (e.g. support from healthcare professionals). However, support does not necessarily map perfectly onto the attributes of social networks. For example, someone with a large social network may actually feel lonely (Suedermann et al, 2013). More precisely, social support can be conceptualized as the functional aspects of social relationships. The most frequently mentioned functions of supportive behaviors are emotional, informational and instrumental support (Alloway & Bebbington, 1987; Thoits, 2011).

Furthermore, social support consists of several sub-constructs (Heller & Swindle, 1983). The most commonly distinguished constructs are received and perceived support. Received social support refers to the actual provision of supportive behaviours from others, while perceived social support refers to the recipients' perception of the availability of support and their satisfaction with it (Sarason & Sarason, 2009). The main difference between the two constructs is that perceived social support refers to the anticipating help in times of need, whereas received social support refers to recalling previously received support in a given time period (Ibarra-Rovillard & Kuiper, 2011). This distinction is important because research has consistently shown stronger links between health and perceived social support (Ibarra-Rovillard & Kuiper, 2011).

Schizophrenia and psychosis

Conceptualisation, epidemiology and comorbidity

Schizophrenia and related psychotic disorders (psychosis) are among the most severe psychiatric disorders, comprising a broad range of symptoms such as delusions, hallucinations and thinking problems (Mueser & McGurk, 2004). The condition can be highly debilitating, interrupts the individual's social and occupational functioning (e.g. van Os et al, 2009), and is associated with burden for the individual, carers, services and society (Kuipers et al, 2006). The estimated lifetime risk of the disorder falls within 0.12% and 1.6% (Mueser & McGurk, 2004), and onset tends to be in early adulthood (i.e. between the ages of 15 and 39 years). Comorbidity rates are high and involve a range of conditions such as substance misuse (Green et al, 2004), depression and anxiety (Freeman & Garety, 2003), suicide, and chronic medical conditions (e.g. HIV; Auquier et al, 2006).

Early Psychosis and Ultra-High Risk (UHR) status

Psychosis is further classified into 'early' and 'chronic' psychosis. Early psychosis refers to those individuals who are experiencing their first or second episode, or had their initial episode within the last two to three years (Baldwin et al, 2005). The first few years after illness onset have been found to be critical for treatment response and outcome (e.g. Birchwood et al, 1997; 2003) with rates of suicide, trauma and anxiety being elevated during this period (Birchwood et al, 2003).

Recent research has moved away from the categorical model of psychosis towards a dimensional model. Evidence shows that symptoms (e.g. hearing voices or paranoia) can fall on a continuum of severity within the general population (e.g. Freeman et al, 2005; van Os et al, 2000; 2009). Differences between service users and no need for care individuals are quantitative rather than qualitative (Kuipers et al, 2006), with the reactions (such as distress) to the unusual experiences differentiating between clinical and non-clinical groups. The majority of people reporting psychosis-like experiences do not go on to develop problems that interfere with their life or require clinical intervention (van Os et al, 2009). However, for some individuals the psychosis-like experiences may gradually increase in severity and frequency and become associated

with distress, particularly in the context of mood and anxiety disturbances. Young and colleagues (1996; 2004) developed a strategy for identifying individuals at high risk of developing psychosis on the basis of these trait and state vulnerability characteristics. Individuals who present with either 1) attenuated psychotic symptoms, 2) Brief Limited Intermittent Psychosis (i.e. BLIPs; Young et al, 2003), or 3) trait vulnerability coupled with a recent decline in socio-occupational functioning were found to have a 40 percent risk of developing psychosis within the following 12 months period (e.g. Fusar-Poli et al, 2013). Fulfilling these criteria thus indicates that an individual is at high risk of imminent psychosis onset, and these individuals are therefore considered to be at 'ultra high risk' (URH) for psychosis.

Social networks and social support in psychosis

Early research on social networks and support in psychosis

People with severe mental health problems, such as psychosis, commonly struggle to develop and maintain functioning relationships and tend to miss out on good social support (e.g. Norman et al, 2005). Early studies of social relationships in this population primarily focused on structural aspects of social networks. A series of studies from the 1970s to the 1990s consistently showed that the network size of service user with a long history of schizophrenia was substantially smaller than in individuals without mental health problems. The average network size of healthy participants found by these studies consisted of 14 to 40 people, who they regularly interacted with and of whom six to ten were known intimately (Cresswell et al, 1992). This compared to an average network size of four to five people who were regularly seen by people with a long history of schizophrenia (Segal & Holschuh, 1991), and of whom most were family members (Pattison et al, 1975; Cresswell et al, 1992). While other clinical groups also have smaller than average social networks, these are typically larger than for people with psychosis. For example, individuals with substance abuse difficulties were found to have a mean social network size of 18.4 (Favazza & Thompson, 1984) and people suffering from depression were found to have an average social network size of five to ten (Pattison et al, 1975).

A different series of studies examined associations between social relationships with outcome variables in people with psychosis. In an early study, Strass and Carpenter (1977) followed-up 131 individuals with schizophrenia who were admitted to three psychiatric centres and evaluated within two weeks of admission and then re-interviewed at two and five years following the initial evaluation. They found that more social support at baseline predicted fewer days in hospital and better perceived quality employment at follow-up. Cohen and Sokolovsky (1979) also examined the link between social networks and outcome. They found that small network size predicted rehospitalisation and psychopathology. Findings on the role of social networks in mental health service utilisation were comprehensively reviewed by Albert and colleagues (1998), who concluded that smaller social networks or lower rates of social support were associated with increased inpatient service use. Interestingly, enhanced support for carers was found to be associated with service users spending fewer days in hospital (Jed, 1989). They also highlighted that a higher proportion of family members (as opposed to friends) in the social networks of service users predicted an increased risk of hospitalisation (Holmes-Eber & Ringer, 1990). The presence of both family members and friends in the social networks of service users was generally associated with better self-care and employment (Evert et al, 2002). Taken together, the findings from the early studies indicate that disrupted social networks and social support deficits are associated with higher levels of psychosis symptomatology, as well as negative social and occupational outcomes in people with psychosis.

Recent studies on social network and support in psychosis

While the majority of early studies compared diagnostic groups when studying the effects of social networks and social support, more recent studies have used continuous measures of psychosis symptoms (e.g. Norman et al., 2005), as these measures are more in line with the continuum models of psychosis (van Os et al., 2010). Most of the studies that utilised continuous symptom measures found that smaller social networks and other network disturbances (such as fewer reciprocal relationships) were predominantly associated with negative symptoms (Hamilton et al. 1989; Macdonald et al. 1998; Bengtsson-Tops and Hansson 2001; Thorup et al. 2006).

However, there is also evidence that links poor social network functioning with both negative and positive symptoms (e.g. Bengtsson-Tops and Hansson, 2001).

Further, whereas early studies of social network and social support in psychosis used samples of individuals with longstanding history of psychotic disorders, more recent studies have started to investigate social networks and social support at the onset of psychosis. These studies have found that the social relationship deficits characteristics of chronic psychosis (such as reduced network size) are already apparent in the very early stages of the disorder (Gayer-Anderson & Morgan, 2012). Even at first episode, the social networks of people with psychosis comprise fewer members, with whom they may have little contact. For example, in a relatively large sample of 175 service users with psychosis and 122 healthy controls, Erickson and colleagues (1989) found that individuals with a first episode of schizophrenia and affective psychosis both had smaller social networks than controls. Similarly, in a sample of 26 individuals with a first episode of psychosis and 26 matched controls, Macdonald and colleagues (2000) found that individuals with a first psychotic episode had on average significantly fewer individuals in their social network compared to matched controls. In addition, data from Morgan and colleagues' (2008) case-control study on social disadvantage, ethnicity and first episode psychosis showed that the networks of people with psychosis tend to contain proportionately more family members, they have fewer confidants, and more people are described as acquaintances. There is also evidence that people with a first episode of psychosis are less likely to be satisfied with the level of support they receive, despite receiving more than they report to give (i.e. despite non-reciprocity) (Reininghous et al, 2008; Tolsdorf, 1976; Horan et al, 2006).

While a number of recent studies have investigated social functioning in people at UHR of developing psychosis (e.g. Jalbrzikowski et al, 2013; Salokangas et al, 2014; Fusar-Poli et al, 2015; Brandizzi, et al 2015), only three studies to date have examined social networks and social support in this population. However, the data have generally added to the notion that poor social networks and support are already present at illness onset (Willhite et al, 2008; Pruessner et al, 2011; DeVlyder & Gearing, 2013). For example, Pruessner and colleagues (2011) examined stress and psychological factors in

individuals with an UHR of developing psychosis, first episode and healthy controls. They found that both UHR individuals and first episode participants had lower social support than controls.

The social network approach versus studies of perceived social support

The social network approach can be distinguished from studies of social support, which is generally conceptualised as contributing positively to the recipient's subjective appraisals (Coyne & DeLongis, 1986; Monroe & Steiner, 1986). The majority of both early and recent studies that examined social relationships in psychosis have focused on quantitative features of the social networks such as size and reciprocity rather than more qualitative and functional aspects such as satisfaction with relationships or the absence or presence of a confidant, with the rationale that effective early treatment could be directed at increasing social contact. In practice, changing the characteristics of social networks has proven difficult (Sensky et al, 2000), and one reason for this may be that some people with psychosis may have difficulties with the motivational skills often required to sustain relationships. Thus, interventions that focus on increasing the number of friends available may not be targeting the right problem. While a number of studies indicate that perceived social support is associated with various indices of positive outcome in chronic psychosis (e.g. Lo & Lo, 1977; Strauss & Carpenter, 1977; Faccincani et al, 1990), it is important to note that not all types of support are equally efficacious and some may actually be a source of stress and strain and perceived as harmful or abusive (Parry, 1988). Social withdrawal may consequently be protective, by insulating the individual from stressful relationships (Cresswell et al, 1992; Delespaul et al, 2002). However, even when someone withdraws in this way, he or she may still feel the effects of lack of support. Thus, by focusing exclusively on those social connections perceived as beneficial, a positive association between support and outcome may be predetermined.

Aim of the current review

In order to determine the current evidence base and to identify areas for future research, a systematic review of studies on perceived social support in individuals at

the onset of psychosis is presented. The key questions I aim to address in the systematic review are:

- (1) Is there evidence that perceived social support at the onset of psychosis (i.e. at first presentation or UHR) has a beneficial effect on clinical features of the disorder (i.e. symptom severity, social functioning or remission rates), or quality of life (QoL) and well-being?
- (2) Is there variation in reported outcome by the type of support provided (i.e. from family, friends, or significant others)?

Method

Data sources

Relevant literature was identified by entering the search terms ('schizophreni*' or 'psychosis' or 'psychotic disorder') and ('first episode') and ('ultra high risk' or 'UHR' or 'clinical high risk' or 'at risk mental state' or 'ARMS') and ('social support') into the search engines of Medline (1964 to April 2015), PsychINFO (1806 to April 2015) and EMBASE (1974 to April 2015). An additional search was carried out using the Tests and Measures tool in PsychINFO to search for specific measures of social support. Search terms included: social support, family support, parental support, spousal support, interpersonal support, emotional support, instrumental support, social relationship, confidant, close person, social interaction, and significant other. Reference lists of included papers were also searched for further relevant articles.

Study selection

Titles and abstracts of identified citations were examined by the author and potential papers for review were selected and read in full. For a paper to be included in the review, the study had to be published in a peer reviewed journal in English up to April 2015 and report data on one or more domains of social support in a sample of individuals either at UHR of psychosis or with a first episode (FE) of psychosis. If data were published repeatedly as a whole, the most inclusive publication was used.

Publications were excluded if: (1) they reported on social networks only, without reporting on one or more domains of social support; (2) if no data on symptom severity, and/or functioning and/or remission, and/or QoL were provided as the outcome measure; (3) if FE was measured by criteria other than the Diagnostic and Statistical Manual of Mental Disorders (DSM; American Psychiatric Association, 2000) or the International Classification of Diseases (ICD; World Health Organisation, 1992); or if (4) UHR was measured by criteria other than the Comprehensive Assessment of At Risk Mental State (CAARMS; Young et al, 2005) or the Structured Interview for Prodromal Syndromes criteria (SIPS; Miller et al., 2002).

Data extraction and synthesis

The following variables were recorded by the author in a structured fashion: (1) study design; (2) sample characteristics (including age and UHR or FE); (3) measure of social support; (4) social support domain(s) (i.e. family, friends, significant other); (5) results (associations with symptom severity, functioning, or remission; or associations with QoL or well-being). The wide variation in methodology, including samples and measures, between studies meant that a non-quantitative approach to synthesizing and presenting findings was adapted (Mays et al. 2001).

Quality assessment

The Evaluation of Public Health Practice Project (EPHPP) Quality Assessment Tool for Quantitative Studies was used to assess the quality of all studies included in the systematic review. The instrument (refer to Appendix 1) provides a standardised evaluation framework to assess study quality and develop recommendations for study findings. The quality appraisal tool was developed as a discrete step within the systematic review process. The EPHPP has been evaluated and it has shown good content and construct validity, as well as inter-rater reliability (Thomas et al, 2004). The EPHPP assesses six methodological dimensions: selection bias, study design, confounders, blinding (this section was not relevant for to the nature of studies included in the present systematic review and thus discounted for the calculation of an overall methodological rating), data collection methods, and withdrawals and

dropouts, all of which feed into the calculation of an overall methodological rating. Each domain is rated on a three-point scale: strong, moderate, or weak. Two additional methodological dimensions provided by the tool, but not included in the overall methodological rating, are intervention integrity and analyses (these were not assessed for the studies included in the present systematic review). A reviewer's dictionary is provided to assist reviewers and maintain standardised results (refer to user manual in Appendix 2). Overall methodological ratings are included in Table 1.

Results

A flow diagram of the identification and exclusion of studies is provided in Figure 1. Eleven papers were identified that met inclusion criteria and these are outlined in Table 1. The studies reviewed here had sample sizes ranging from 30 to 578, and included varying populations with psychosis or schizotypy or prodromal symptoms (admitted to hospital and community samples), with varying age ranges (from mean ages of 14 years to 32 years), and used a wide range of measures of perceived social support. These methodological variations pose significant challenges to comparing findings and drawing conclusions, and their implications are considered in detail within the discussion. The following section will focus on describing findings.

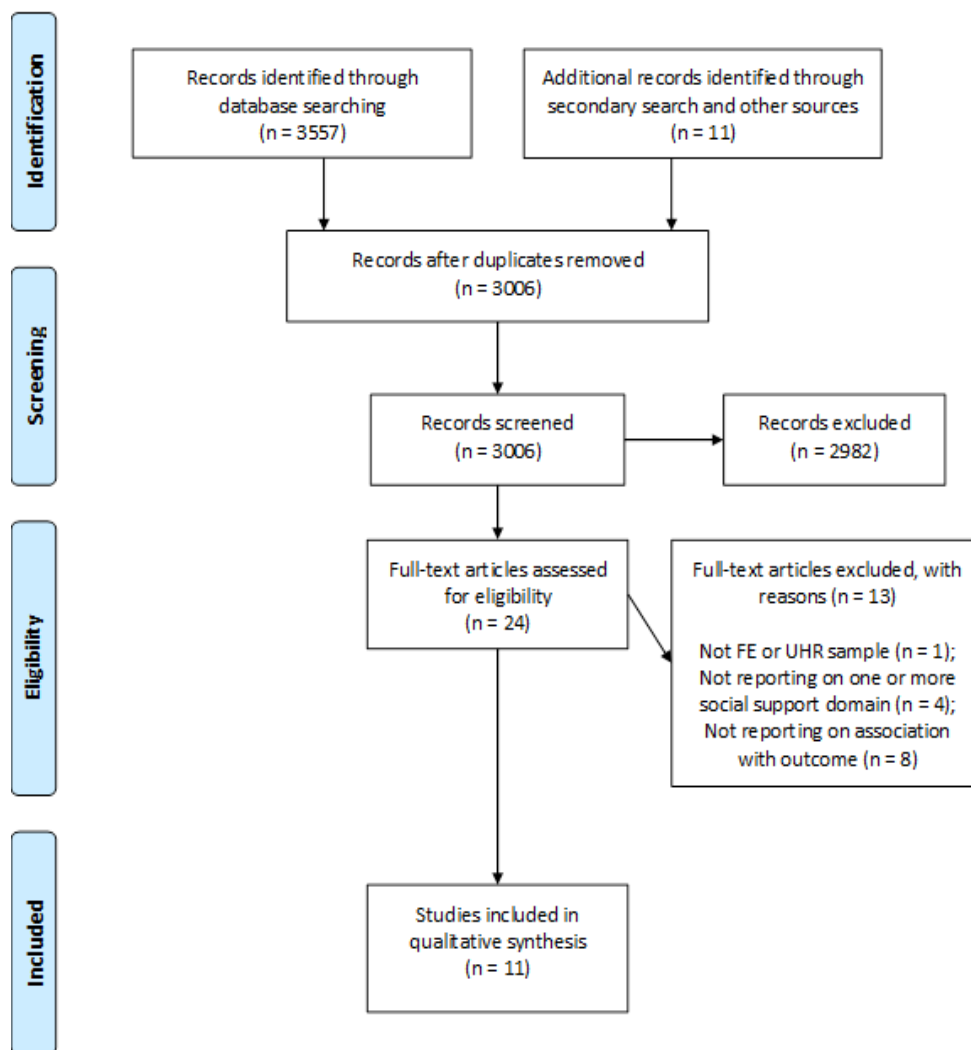


Figure 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Diagram of selected studies

Table 1 Overview of studies included in the review

Study	Country	Design	Diagnosis	n	Mean age	Social support measure(s)	Support Domain (s)	Outcome	Overall quality rating
DeVylder & Gearing, 2013	Canada	Retrospective Cohort Study	FE (admitted to hospital or community sample)	84	14.7	Clinical judgment	Declining vs. stable perceived support from peers	Significant association between increase in negative symptoms and declining peer support	Weak
Suedermann et al, 2013	UK	Cross-sectional	FE (community sample)	38	32.3	MDSS	Perceived availability of support from family and friends	Significant association between greater satisfaction with support from friends and family and reduced positive and negative symptoms	Moderate
							Perceived satisfaction with support from family and friends		
							Perceived availability of support from experts	No association between functioning and perceived social support	
							Perceived satisfaction with support from experts		
						Confidant questionnaire	Presents or absence of a confidant	Significant association between absence of a confidant and increased negative and positive symptoms	
Tempier et al, 2013	UK	Longitudinal Cohort Study	FE (community sample)	123	26.3	SOS	Perceived emotional support	Significant association between greater emotional support and better remission	Weak
							Perceived practical support	No association between practical support and remission	
Norman et al, 2012	Canada	Longitudinal Cohort Study	FE (community sample)	132	23.8	WQL-P	Perceived support from family and friends	Significant association between greater support at baseline and at 1 year FU and higher functioning	Moderate

Table 1 Overview of studies included in the review cont.

<i>Study</i>	<i>Country</i>	<i>Design</i>	<i>Diagnosis</i>	<i>n</i>	<i>Mean age</i>	<i>Social support measure(s)</i>	<i>Support Domain (s)</i>	<i>Outcome</i>	<i>Overall quality rating</i>
Pruessner et al, 2011	Canada	Cross-sectional	UHR (community sample)	30	20.3	MDSS	Total MDSS score	Significant association between lower perceived support with higher negative symptoms in UHR group	Moderate
			FE (community sample)	32	22.7			Significant association between greater perceived support with better functioning in UHR group	
								No associations between perceived support and outcome in FE group	
Song et al, 2011	Korea	Cross-sectional	FE (admitted to hospital or community sample)	48	24.1	ISEL	Total ISEL score	Significant association between greater perceived support with better QOL	Moderate
Uzenoff et al,2010	USA	Cross-sectional	FE (community sample)	41	22.3	MDSS	Total MDSS score	Significant association between greater perceived support and better well-being and QOL	Moderate
								Significant association between greater perceived support and reduced positive symptoms and reduced total symptoms	
Thorup et al, 2007	Denmark	Retrospective Cohort Study	FE (admitted to hospital or community sample)	578	26.5	Social Network Schedule	Perceived quality and quantity of support	Significant association between perceived quantity of support and premorbid social functioning	Moderate
Norman et al, 2005	Canada	Longitudinal Cohort Study	FE (community sample)	113	25.8	WQL-P	Total WQL-P score	Significant association between perceived support at 3 yrs. FU and reduced positive symptoms	Moderate
Erickson et al, 1998	Canada	Prospective Cohort Study	FE (admitted to hospital or community sample)	175	22.7	ISSI	Perceived availability of social support Perceived adequacy of social support	No association between perceived availability or adequacy of support with adaptive functioning	Moderate
Erickson et al, 1989	Canada	Prospective Cohort Study	FE (admitted to hospital or community sample)	175	25.2	ISSI	Perceived availability of social support Perceived adequacy of social support	Significant association between greater availability and adequacy of support from acquaintances and better adaptive functioning	Moderate

FE, First Episode; FU, Follow-up; ISEL, Interpersonal Support Evaluation List; ISSI, Interview Schedule for Social Interaction; MDSS, Multidimensional Support Scale; QoL, Quality of Life; SOS, Significant Other Scale; UHR, Ultra High Risk; UK, United Kingdom; USA, United States of America; WQL-P, Wisconsin Quality of Life Scale – Provider Questionnaire

Quality Assessment

The quality assessment of the studies included in the present review was conducted using the EPHPP tool. All studies were evaluated as moderate or weak in the overall methodological rating. A detailed assessment of study qualities is presented in Table 2 below. Only one study included a sample representative of the population (Thorup et al, 2007), and this study was rated as strong on selection bias. Half of the remaining ten studies (Suedermann et al, 2013; Norman et al, 2012; Pruessner et al, 2011; Uzenoff et al, 2010; Norman et al, 2005) were rated as moderate on selection bias due to the rate (i.e. 60% to 79%) of selected individuals agreeing to participate in the study. None of the studies were rated as strong in their study design, and most studies were rated as weak due to cross-sectional or retrospective study design (Suedermann et al, 2013; DeVlyder & Gearing, 2013; Tempier et al, 2013; Song et al, 2011; Pruessner et al, 2013; Uzenoff et al, 2010; Thorup et al, 2007). Only one study (Uzenoff et al, 2010) accounted for most (i.e. 80% to 100%) confounders, and this study was rated as strong. Three studies accounted for some (i.e. 60%-79%) confounders (Song et al, 2011, Pruessner et al, 2011; Norman et al, 2005), and the remaining studies were rated as weak (Suedermann et al, 2013; DeVlyder & Gearing, 2013; Tempier et al, 2013; Norman et al, 2012; Thorup et al, 2007; Erickson et al, 1998; 1989). Six out of the eleven studies reported evidence of validity and reliability for their measurement instruments, and these were rated as strong (Suedermann et al, 2013; Song et al, 2011; Pruessner et al, 2012; Uzenoff et al, 2010; Erickson et al, 1998; 1989). Regarding the withdrawals and dropout criteria, only those studies that reported more than 80% of participants completing the study obtained a strong rating (Suedermann et al, 2013; DeVlyder & Gearing, 2013; Thorup et al, 2007).

Table 2 Quality assessment results of studies included in this review

	Selection bias	Study design	Confounders	Data collection method	Withdrawals and Drop-out	Overall rating
Suedermann et al, 2013	Strong	Weak	Weak	Strong	Strong	Strong
DeVylder & Gearing, 2013	Weak	Weak	Weak	Weak	Strong	Weak
Tempier et al, 2013	Weak	Weak	Weak	Weak	Moderate	Weak
Norman et al, 2012	Strong	Moderate	Weak	Weak	Moderate	Moderate
Song et al, 2011	Weak	Weak	Moderate	Strong	Weak	Moderate
Pruessner et al, 2011	Strong	Weak	Moderate	Strong	Weak	Moderate
Uzenoff et al, 2010	Strong	Weak	Strong	Strong	Weak	Moderate
Thorup et al, 2007	Strong	Weak	Weak	Weak	Strong	Moderate
Norman et al, 2005	Strong	Moderate	Moderate	Weak	Moderate	Moderate
Erickson et al, 1998	Weak	Moderate	Weak	Strong	Moderate	Moderate
Erickson et al, 1989	Weak	Moderate	Weak	Strong	Moderate	Moderate

Strong
 Moderate
 Weak

Is there evidence that perceived social support has beneficial effects on clinical features?

Nine out of the eleven studies included in this review investigated associations between perceived social support and symptom severity or functioning. Two of these nine studies explored associations between perceived social support and both symptom severity and functioning (i.e. Suedermann et al, 2013; Pruessner et al, 2011). In addition, four studies investigated associations between perceived social support and functioning alone (i.e. Norman et al, 2012; Thorup et al, 2007; Erickson et al, 1998; 1989), and a further three studies examined associations between perceived social support and symptom severity only (i.e. DeVlyder & Gearing, 2013; Uzenoff et al, 2010; Norman et al, 2005).

In regard to symptom severity, all five studies found a significant beneficial effect of perceived social support on symptoms (i.e. an association between greater perceived social support with reduced symptom severity). However, it is unclear whether these effects are on positive or negative symptoms. In a longitudinal study of 113 individuals with first episode psychosis, Norman and colleagues (2005) found higher perceived social support was predictive of lower positive symptoms at three years follow-up ($r = 0.33$; $p < 0.01$), and this relationship was independent of confounders such as age, gender, premorbid adjustment and duration of untreated illness. Others, however, have found either a negative association between perceived social support and negative symptoms or no associations at all. For example, Pruessner and colleagues (2011) compared perceived social support in 32 service users with a first episode of psychosis, 30 individuals at UHR of psychosis and 30 healthy controls, and assessed associations with symptoms in both groups. They found no association between perceived social support and symptoms in the first episode of psychosis group. However, in the UHR group lower perceived social support was associated with higher negative symptoms ($\beta = -0.51$; $p < 0.01$). Similarly, in a retrospective cohort study of 84 adolescents prior to hospitalisation for a first episode of psychosis, DeVlyder and Gearing (2013) found that lower perceived social support prior to the index hospitalisation was related to negative symptoms ($\beta = 0.65$; $p < 0.001$). The authors argued that the reduction in perceived social support was a consequence of the onset of the disorder/symptoms. Arguably the most sophisticated and thorough investigations of perceived social support at the onset of psychosis was conducted in a recent study by Suedermann and colleagues (2013), who examined and reported on several social support domains (i.e. perceived satisfaction with support and perceived availability of support through family, friends and significant others) in a sample of 38 individuals with a first episode of psychosis. The authors found that lower satisfaction with social support from both family members and friends was associated with more severe current positive as well as negative symptoms.

With regard to functioning, the literature suggests that perceived social support does have beneficial effects, with several longitudinal studies reporting on associations between perceived social support and functioning (Erickson, 1989, 1998; Thorup et al,

2007; Norman et al, 2012). For example, Erickson and colleagues (1989) found that greater perceived availability and adequacy of acquaintances were associated with better overall adaptive functioning at 18 months follow up ($r = 0.25$; $p < 0.05$; and $r = 0.35$; $p < 0.01$ respectively). These associations, however, were present only within the schizophrenia group (as compared to the affective psychosis group) and disappeared at five-year follow-up (Erickson et al, 1998). Similarly, Norman and colleagues (2012) reported that greater perceived social support at baseline and at one year post treatment served as independent predictors of better functioning (defined as more weeks spent in employment, less weeks spent on disability pension, as well as total Global Assessment of functioning score) at five-year follow up. More recent cross-sectional studies do not find these protective effects on function. For example, in their study of 38 individuals with a first episode of psychosis, Suedermann and colleagues (2013) did not find an association between overall functioning with any social support variables. Similarly, Pruessner and colleagues (2013) did not find any association between overall functioning and perceived social support of 32 individuals with a first psychosis episode. However, the same study reported an association between greater perceived social support and better overall functioning in the UHR group ($r = 0.62$; $p < 0.01$).

Finally, only one study examined any beneficial effects of perceived social support on sustained remission (defined as low to mild symptom severity over a six month period) in service users with early episode psychosis at 18 months follow up (Tempier et al, 2013). Interestingly, this study investigated perceived availability of emotional support and practical support separately, and found that perceived availability of emotional support predicted a longer time spent in remission ($r = 0.01$; $p < 0.01$), independent of age, gender and treatment group. Perceived availability of practical support was not found to be associated with remission. This study further investigated potential mediating effects of perceived emotional support in paths from network size and hours of contact with family on remission at 18 follow up. This analysis revealed total mediation, indicating that both social network size and hours of family contact are only advantageous to remission through their effect on perceived emotional support.

Is there evidence that perceived social support has beneficial effects on QoL?

Only two studies investigated potential beneficial effects of perceived social support on QoL. Psychological well-being is a subjective component of QoL. In a relatively recent cross-sectional study, Uzenoff and colleagues (2010) examined predictors of well-being in 41 individuals with first episode psychosis. They found that greater perceived social support was a significant predictor of well-being ($\beta = 0.90$; $p = 0.02$). Similarly, Song and colleagues (2011) examined possible associations between QoL and perceived social support in a sample of 48 service users with first episode psychosis. They found that greater perceived social support was associated with overall better QoL, as well as with several QoL subdomains (such as motivation and curiosity).

Is there variation by the type of support provided (i.e. from family, friends, or significant others)?

The majority of studies (i.e. 64%) to date did not investigate potential beneficial effects of perceived social support separately for different social support types or domains (Tempier et al, 2013; Pruessner et al, 2011; Song et al, 2011; Uzenoff et al, 2010; Thorup et al, 2007; Norman et al, 2005; 2012). The only study that did examine the effects of perceived satisfaction (and availability) of support from family members, friends as well as experts found that both greater satisfaction with support from family members and friends, but not experts, was associated with decreased symptom severity (Suedermann et al, 2013). There is, however, also evidence suggesting that support from non-family members has greater beneficial effects on negative symptoms and functioning. For example, DeVlyder and Gearing (2013) reported that reduced peer support was associated with an increase in symptom severity (although this study did not investigate the effects of any other support domains). Similarly, Suedermann and colleagues (2013) included a separate measure on the presence or absence of a confidant in their study and found that the absence of a confidant was more strongly associated with negative symptom severity. Perceived social support from non-family members was also found to predict adaptive functioning at both 18 months and five year follow up (Erickson et al, 1998). Some studies further suggest

that perceived social support from family members has negative effects on outcome. For example, Tempier and colleagues (2013) separately investigated the perceived availability of support from family members (measured as contact with family) and found that moderate family contact predicted shorter remission duration at 18 months follow up. Equally, a negative association between perceived support from family members and adaptive functioning at 18 months follow up was found in a group of individuals with a first episode (Erickson et al, 1989), although this association disappeared at five years follow up.

Discussion

This review, to the best of the author's knowledge, is the first to systematically examine the beneficial effects of perceived social support in early psychosis.

Social support and symptom severity

Tentatively, the results indicate a beneficial effect of perceived social support at the onset of psychosis on symptom severity, although it is unclear whether these effects are on positive or negative symptoms with studies reporting either or both. This is in line with both early and more recent studies of social networks in psychosis that have similarly shown mixed results in regard to associations with symptom severity (e.g. Hamilton et al, 1989, Thorup et al, 2006).

The results of this review also indicate beneficial effects of perceived social support from both family and friends on symptom severity, with greater support leading to symptom reduction. There is also evidence that perceived social support from non-family members has greater beneficial effects on negative symptoms and functioning, and that perceived social support from family members has negative effects on outcome (i.e. leading to shorter remission and reduced adaptive functioning). These findings are in line with early studies of social support and social networks in psychosis that have shown higher proportions of family members in the social networks of service users to predicted increased risk of re-hospitalisation (e.g. Holmes-Eber & Ringer, 1990; Albert et al, 1998). Our findings also link to research on help-seeking in

individuals with psychosis. This research has repeatedly identified an important role of significant others in accessing mental health care for individuals with psychosis onset (e.g. Morgan et al, 2006). Service users do not usually seek services on their own, but rather tend to be directed by their parents, other family members or the police (Boydell & Gladstone, 2006). In a qualitative study, Boydell and Gladstone (2006) investigated decisions to help-seeking in young individuals experiencing first episode psychosis. They reported that in a subset of these individuals, elements of persuasion and force through family members was present in the descriptions of how they came to mental health services. It is possible that family members may be perceived as critical and this may explain some of the indicated negative effects of perceived social support from family members on outcome.

Social support and functioning

In regard to beneficial effects of perceived social support on functioning, the picture is more unclear. While the longitudinal, retrospective or prospective studies reviewed revealed positive associations (e.g. Norman et al, 2012; Thorup et al, 2007; Erickson et al, 1998), the cross-sectional studies reviewed found no associations in individuals with a first episode (e.g. Suedermann et al, 2013; Pruessner et al, 2011). This is with the exception of one recent cross-sectional study that found a similar association in individuals at UHR as was found in the longitudinal studies (Pruessner et al, 2011). Previous, early studies of social support and networks in psychosis have repeatedly demonstrated that social support deficits are associated with negative social and occupational functioning (e.g. Strauss & Carpenter, 1977; Evert et al, 2002). It is interesting therefore, that most cross-sectional studies reviewed (e.g. Suedermann et al, 2013) were conducted much more recently than (some of) the retrospective cohort studies included in this review (e.g. Erickson et al, 1998). It is questionable then whether the difference in results may be related to study design. This would however not explain the negative association between perceived social support and functioning found by Pruessner and colleagues (2011) in the UHR group of their study. The authors suggested that the difference between groups (i.e. FE and UHR) might be explained by treatment effects. Individuals with a first episode had started to receive antipsychotic

medication, intensive clinical case management and various individual, group and family interventions.

Social support and remission

In regard to beneficial effects of perceived social support at the onset of psychosis on remission and quality of life, the results are less ambiguous. Although very few in nature (Tempier et al, 2013; Song et al, 2011; Uzenoff et al, 2010), these studies provide strong evidence for beneficial effects. Furthermore, Tempier and colleagues' (2013) study investigating effects of perceived social support on remission was the only study that investigated different social support functions (i.e. emotional and practical). Investigating functional aspects of social support separately does, however, seem to be important, as the result of this study found beneficial effects of perceived emotional support only.

Understanding the pathways through which social support may be helpful or harmful to mental health

Although the results of this review generally indicate that perceived social support at the onset of psychosis has beneficial effects on outcome, little is known about the mechanism through which this effect occurs. To date, there has been little research which has systematically investigated pathways between (perceived) social support and mental health. One of the first studies was conducted by Cohen and Wills (1985), who differentiated between main effects of social support on health, and 'stress-buffering' effects (indirect effects). Stress buffering occurs when social support protects (or "buffers") people from the negative effects of stress (Lahey & Orehek, 2011) by facilitating coping. The general notion is that stress-buffering effects occur either by strengthening protective factors and/or reducing the negative impact of the stressful event on well-being (Ibarra-Rovillard & Kuiper, 2011). For example, social support may either reduce negative reactions to stressors or dampen physiological/behavioural responses to stress. In contrast, lower social support is supposed to lead to negative appraisals of the situation and consequently impact adversely on mental health. Cohen and Wills (1985) suggested that stress buffering

only occurs in the presence of stress, whereas in the absence of stress, social support is not linked to mental health. Empirical support for this model is limited. Furthermore, there have been several criticisms of the stress buffering model. For example, while the stress-buffering theory proposes that social support only has indirect beneficial effects in the presence of stress, more recent research suggests direct effects of social support on mental health, especially emotional support, even in the absence of stress (e.g. Thoits, 2011; Turner & Llyd, 1999). Moreover, while the stress-buffering theory assumes that perceived social support is a veridical account of received social support, evidence suggests that received and perceived social support are not, or only weakly correlated (Lahey & Orehek, 2011).

Relational Regulation Theory (RRT) was proposed by Lahey and Orehek (2011) to explain the well-established main effect between perceived social support and mental health, which cannot be accounted for by the stress-buffering theory. RRT builds on attachment research and capitalises on the idea that human interactions elicit affect, action and thought. According to RRT, perceived social support does not directly cause affect but emerges from the types of social interaction that successfully regulate affect. For example, a distressed person speaking to his friend about his relationship breakup may feel more hopeful after the conversation not because of concrete coping tips received, but because of a positive affect (i.e. a sense of belongingness) resulting from relating to the friend.

The stress-buffering theory and RRT can be seen as important advances in understanding the pathways through which social support may be helpful or harmful to mental health. However, they do not specifically address the link between perceived social support and outcome in psychosis. Cognitive models of positive symptoms emphasise the importance of factors responsible for the maintenance of psychotic appraisal (Bentall et al, 1994; Garety et al, 2001), such as biased reasoning processes, emotional processes, dysfunctional schema and adverse social environments. However, although Garety and colleagues (2001) mention adverse social environments as one factor impacting negatively on psychotic appraisal, they do not specifically describe the pathway through which both are causally linked.

The only study reviewed that addressed potential mechanism through which perceived social support at the onset of psychosis might have beneficial effects on outcome is provided by Suedermann and colleagues (2013). In a secondary analysis, the authors report that anxiety mediates (at least partially) the association between loneliness (i.e. a subset of perceived social support) and paranoia in individuals with a first episode of psychosis. The authors suggest that anxiety may therefore be one potential pathway through which loneliness may drive paranoia. That is, the authors suggest that loneliness may distort thinking processes by exaggerating threat appraisals, or alternatively that people may find it harder to think of alternatives to their unusual ideas because they have no one to discuss them with and that this may raise anxiety levels which in turn exacerbate paranoia. Although the suggested pathway by Suedermann and colleagues (2013) is promising, further studies with larger samples of both first episode and UHR populations will need to replicate these findings.

Methodological consideration

The overriding impression that emerges from this literature review is the marked methodological heterogeneity of the available studies; this is evident in study design, sampling, sample size and ages of samples, measures used, as well as the way in which perceived social support and its domains are conceptualised. Measurement of perceived social support is a good example in which the methodologies employed varied considerably. In studies that used a specific (valid and reliable) measure of perceived social support (e.g. Suedermann et al, 2013) individuals were asked to name friends, family members and significant others separately, as well as rate their perceived availability of and satisfaction with the support provided by these individuals. In contrast, other studies asked individuals to name only those people who they were close to or had contact with within a specified date range (e.g. within the last month; Thorup et al, 2007). Moreover, most measures set a limit on the number of individuals that could be named. Further, it seems that beneficial effects of perceived social support are a function of contact and support from friends (not family). Consequently, summing total numbers of contacts with others may be misleading and it is evidently problematic to draw comparisons. Similarly, assessment of support

tended to be generic (with only limited consideration of the multidimensional character of support) and most studies did not inquire about the different functional aspects of social support (i.e. emotional, instrumental, practical), which seem to, however, have varying importance on outcome (Tempier et al, 2013).

There are other substantive methodological issues that limit what can be inferred from the available literature, at least in relation to our questions concerning the possible impact of perceived social support at the onset of psychosis on outcome. These include selection bias (e.g. use of inpatient samples and non-random selection), information bias (e.g. use of study specific, non-validated assessments of perceived social support and limited attention to issues of reliability), confounding variables (i.e. few studies adjusted for alternative variables that might explain observed associations) and direction of causation (i.e. several studies were cross-sectional making it difficult to disentangle cause and effect). Further, access to and perceptions of social support will inevitably change over time; the greater the distance between life events and the measure of perceived social support, the less likely the measure is to capture the availability of support at the time of the event, which poses a major limitation to retrospective studies (Gayer-Anderson & Morgan, 2012). A detailed assessment of study qualities is presented in Table 2. The low number of studies addressing specific confounding variables constitutes a particular difficulty to the conclusions that can be drawn, specifically in regard to potential beneficial effects of perceived social support on social functioning. Cognitive deficits have repeatedly been shown to predict social and functional impairment in individuals with schizophrenia, and social cognition (including Theory of Mind; ToM) has been directly related to social functioning (Bora et al, 2006). More recent research has demonstrated substantial impairments in ToM in individuals with a first episode of psychosis and those at UHR. It is possible that impairments in ToM in these individuals leads to perception of less social support and particular more dissatisfaction with the available social support, and this brings into question the genuineness of reported associations between perceived social support and social functioning by studies.

All of these methodological considerations make comparison and synthesis of the studies reviewed difficult, and caution is therefore required in the conclusions drawn.

Recommendations for future research

The above considerations mean that, at this stage, our understanding of the protective effects of perceived social support in early psychosis is limited. This noted, the evidence does tentatively suggest that perceived social support, particularly from friends and confidants, at illness onset is beneficial to outcome. One way in which this may happen is that greater perceived support following specific life events may mitigate the consequent distress and buffer individuals against the deleterious effects of stress. However, Thoits (1982) argues that this model is confounded in research because life events often consist of losses or gains of supportive relationships, and results will consequently sometimes be biased in favour of this buffering hypothesis. Horan et al. (2006) argue that social support research is further biased by the fact that studies tend to only consider beneficial relationships, despite the fact that negative responses from others within social networks (i.e. negative social support) may have compounding effects (Taylor & Aspinwall, 1996, p. 94).

Additionally, little is known about the specific mechanisms by which perceived social support effects outcome. The relative absence of studies addressing the specific mechanisms by which perceived social support effects outcome is remarkable given that research on social relationships has been conducted for over 30 years, and it suggests an important area for future research. Qualitative research may be one way to gain valuable information regarding mechanisms of change, and this could address both service users and individuals within their social networks. Such research might also be able to answer questions, such as ‘what is it about support that is perceived as beneficial?’, ‘what does good quality emotional support look like?’, and ‘Is there a difference depending on the age of the service user or the situation?’.

Moreover, a fast growing body of research has started to model the possible interplay between several already known (social) psychosis risk factors (e.g. childhood adversity and adversity in adult life) through mediation or moderation analyses. There are a

number of possibilities of how social factors may relate to each other in pathways to psychosis. Some social factors may impact on risk indirectly by increasing likelihood of exposure to more proximal risk factors. On the other hand, social factors may also combine to increase risk. It seems then that perceived social support may be only one piece in a complex illness matrix, and that its protective effects may have the potential to mediate or moderate one or more psychosis risk factors.

Investigating the relationship between social support, onset of psychosis and outcome is not straightforward. A challenge that all research in this area faces is that psychosis, by its very nature, impacts on individuals' social circumstances. Disentangling cause and effect represents an ongoing problem. In responding to this challenge, it is often concluded that longitudinal studies are required. It also ignores the strengths of case-control studies, which – if well designed and fulfilling certain conditions (Susser et al. 2006) – do allow inferences about causation. There is, then, a need for a more mixed economy of research. In this, there is a place for general population studies of the extended psychosis phenotype which, by virtue of being much more common, allows for informative cohort studies to be conducted more feasibly (i.e. with smaller numbers over shorter periods). There is equally a place for carefully designed case-control studies, with the advantages that clinical disorder can be studied and that a wide range of exposures (including potential confounders, effect modifiers and mediators) can be measured. Finally, there may be a place for qualitative research in both clinical samples and their social networks. Where there is then convergence of evidence from studies using different designs, our confidence in the validity of the findings and their applicability to clinical disorder, as well as subclinical phenomena in the general population, will be increased.

These methodological issues notwithstanding, there is evident need for more robust research on the protective effects of perceived social support and early psychosis, and the specific mechanisms through which these effects occur. Such research may provide important clues about what can be done to both prevent onset and increase the likelihood of positive outcomes.

Conclusion

In conclusion, this review indicates that perceived social support has potential protective effects at the onset of psychosis. Most studies reviewed point in the same direction: perceived social support at the onset of psychosis has beneficial effects on symptom severity, functioning, remission rates and quality of life. Tentatively, these effects appear to be a function specifically of perceived support from friends and confidants (rather than family members). However, this review was limited by a relatively small number of suitable and available studies and therefore caution is required in the conclusions drawn. Also, studies included in this review varied in sample characteristics and the social support measurement used, both of which have the potential to influence the results of individual studies. Studies employing several valid and reliable measures of perceived social support and its multidimensional aspects are needed to identify specific beneficial properties systematically. Finally, future studies should move on to investigate the potential mediating and moderating effects of perceived social support in pathways to psychosis.

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Appendices

Appendix 1: The EPHPP Quality Assessment Tool

QUALITY ASSESSMENT TOOL FOR QUANTITATIVE STUDIES



COMPONENT RATINGS

A) SELECTION BIAS

(Q1) Are the individuals selected to participate in the study likely to be representative of the target population?

- 1 Very likely
- 2 Somewhat likely
- 3 Not likely
- 4 Can't tell

(Q2) What percentage of selected individuals agreed to participate?

- 1 80 - 100% agreement
- 2 60 - 79% agreement
- 3 less than 60% agreement
- 4 Not applicable
- 5 Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

B) STUDY DESIGN

Indicate the study design

- 1 Randomized controlled trial
- 2 Controlled clinical trial
- 3 Cohort analytic (two group pre + post)
- 4 Case-control
- 5 Cohort (one group pre + post (before and after))
- 6 Interrupted time series
- 7 Other specify _____
- 8 Can't tell

Was the study described as randomized? If NO, go to Component C.

No Yes

If Yes, was the method of randomization described? (See dictionary)

No Yes

If Yes, was the method appropriate? (See dictionary)

No Yes

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

A) CONFOUNDERS

(Q1) Were there important differences between groups prior to the intervention?

- 1 Yes
- 2 No
- 3 Can't tell

The following are examples of confounders:

- 1 Race
- 2 Sex
- 3 Marital status/family
- 4 Age
- 5 SES (income or class)
- 6 Education
- 7 Health status
- 8 Pre-intervention score on outcome measure

(Q2) If yes, indicate the percentage of relevant confounders that were controlled (either in the design (e.g. stratification, matching) or analysis)?

- 1 80–100% (most)
- 2 60–79% (some)
- 3 Less than 60% (few or none)
- 4 Can't Tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

B) BLINDING

(Q1) Was (were) the outcome assessor(s) aware of the intervention or exposure status of participants?

- 1 Yes
- 2 No
- 3 Can't tell

(Q2) Were the study participants aware of the research question?

- 1 Yes
- 2 No
- 3 Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

C) DATA COLLECTION METHODS

(Q1) Were data collection tools shown to be valid?

- 1 Yes
- 2 No
- 3 Can't tell

(Q2) Were data collection tools shown to be reliable?

- 1 Yes
- 2 No
- 3 Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

A) WITHDRAWALS AND DROP-OUTS

(Q1) Were withdrawals and drop-outs reported in terms of numbers and/or reasons per group?

- 1 Yes
- 2 No
- 3 Can't tell
- 4 Not Applicable (i.e. one time surveys or interviews)

(Q2) Indicate the percentage of participants completing the study. (If the percentage differs by groups, record the lowest).

- 1 80 -100%
- 2 60 - 79%
- 3 less than 60%
- 4 Can't tell
- 5 Not Applicable (i.e. Retrospective case-control)

RATE THIS SECTION	STRONG	MODERATE	WEAK	
See dictionary	1	2	3	Not Applicable

B) INTERVENTION INTEGRITY

(Q1) What percentage of participants received the allocated intervention or exposure of interest?

- 1 80 -100%
- 2 60 - 79%
- 3 less than 60%
- 4 Can't tell

(Q2) Was the consistency of the intervention measured?

- 1 Yes
- 2 No
- 3 Can't tell

(Q3) Is it likely that subjects received an unintended intervention (contamination or co-intervention) that may influence the results?

- 4 Yes
- 5 No
- 6 Can't tell

C) ANALYSES

(Q1) Indicate the unit of allocation (circle one)

community organization/institution practice/office individual

(Q2) Indicate the unit of analysis (circle one)

community organization/institution practice/office individual

(Q3) Are the statistical methods appropriate for the study design?

- 1 Yes
- 2 No
- 3 Can't tell

(Q4) Is the analysis performed by intervention allocation status (i.e. intention to treat) rather than the actual intervention received?

- 1 Yes
- 2 No
- 3 Can't tell

GLOBAL RATING

COMPONENT RATINGS

Please transcribe the information from the gray boxes on pages 1-4 onto this page. See dictionary on how to rate this section.

A	SELECTION BIAS	STRONG	MODERATE	WEAK
		1	2	3
B	STUDY DESIGN	STRONG	MODERATE	WEAK
		1	2	3
C	CONFOUNDERS	STRONG	MODERATE	WEAK
		1	2	3
D	BLINDING	STRONG	MODERATE	WEAK
		1	2	3
E	DATA COLLECTION METHOD	STRONG	MODERATE	WEAK
		1	2	3
F	WITHDRAWALS AND DROPOUTS	STRONG	MODERATE	WEAK
		1	2	3
				Not Applicable

GLOBAL RATING FOR THIS PAPER (circle one):

- | | | |
|---|----------|----------------------------|
| 1 | STRONG | (no WEAK ratings) |
| 2 | MODERATE | (one WEAK rating) |
| 3 | WEAK | (two or more WEAK ratings) |

With both reviewers discussing the ratings:

Is there a discrepancy between the two reviewers with respect to the component (A-F) ratings?

No Yes

If yes, indicate the reason for the discrepancy

- | | |
|---|---|
| 1 | Oversight |
| 2 | Differences in interpretation of criteria |
| 3 | Differences in interpretation of study |

Final decision of both reviewers (circle one):

- | | |
|---|----------|
| 1 | STRONG |
| 2 | MODERATE |
| 3 | WEAK |

Appendix 2: The EPHPP Quality Assessment Tool User Manual

Quality Assessment Tool for Quantitative Studies Dictionary



The purpose of this dictionary is to describe items in the tool thereby assisting raters to score study quality. Due to under-reporting or lack of clarity in the primary study, raters will need to make judgements about the extent that bias may be present. When making judgements about each component, raters should form their opinion based upon information contained in the study rather than making inferences about what the authors intended.

A) SELECTION BIAS

(Q1) Participants are more likely to be representative of the target population if they are randomly selected from a comprehensive list of individuals in the target population (score very likely). They may not be representative if they are referred from a source (e.g. clinic) in a systematic manner (score somewhat likely) or self-referred (score not likely).

(Q2) Refers to the % of subjects in the control and intervention groups that agreed to participate in the study before they were assigned to intervention or control groups.

B) STUDY DESIGN

In this section, raters assess the likelihood of bias due to the allocation process in an experimental study. For observational studies, raters assess the extent that assessments of exposure and outcome are likely to be independent. Generally, the type of design is a good indicator of the extent of bias. In stronger designs, an equivalent control group is present and the allocation process is such that the investigators are unable to predict the sequence.

Randomized Controlled Trial (RCT)

An experimental design where investigators randomly allocate eligible people to an intervention or control group. A rater should describe a study as an RCT if the randomization sequence allows each study participant to have the same chance of receiving each intervention and the investigators could not predict which intervention was next. If the investigators do not describe the allocation process and only use the words 'random' or 'randomly', the study is described as a controlled clinical trial.

See below for more details.

Was the study described as randomized?

Score YES, if the authors used words such as random allocation, randomly assigned, and random assignment.

Score NO, if no mention of randomization is made.

Was the method of randomization described?

Score YES, if the authors describe any method used to generate a random allocation sequence.

Score NO, if the authors do not describe the allocation method or describe methods of allocation such as alternation, case record numbers, dates of birth, day of the week, and any allocation procedure that is entirely transparent before assignment, such as an open list of random numbers of assignments.

If NO is scored, then the study is a controlled clinical trial.

Was the method appropriate?

Score YES, if the randomization sequence allowed each study participant to have the same chance of receiving each intervention and the investigators could not predict which intervention was next. Examples of appropriate approaches include assignment of subjects by a central office unaware of subject characteristics, or sequentially numbered, sealed, opaque envelopes.

Score NO, if the randomization sequence is open to the individuals responsible for recruiting and allocating participants or providing the intervention, since those individuals can influence the allocation process, either knowingly or unknowingly.

If NO is scored, then the study is a controlled clinical trial.

Controlled Clinical Trial (CCT)

An experimental study design where the method of allocating study subjects to intervention or control groups is open to individuals responsible for recruiting subjects or providing the intervention. The method of allocation is transparent before assignment, e.g. an open list of random numbers or allocation by date of birth, etc.

Cohort analytic (two group pre and post)

An observational study design where groups are assembled according to whether or not exposure to the intervention has occurred. Exposure to the intervention is not under the control of the investigators. Study groups might be non-equivalent or not comparable on some feature that affects outcome.

Case control study

A retrospective study design where the investigators gather 'cases' of people who already have the outcome of interest and 'controls' who do not. Both groups are then questioned or their records examined about whether they received the intervention exposure of interest.

Cohort (one group pre + post (before and after))

The same group is pretested, given an intervention, and tested immediately after the intervention. The intervention group, by means of the pretest, act as their own control group.

Interrupted time series

A time series consists of multiple observations over time. Observations can be on the same units (e.g. individuals over time) or on different but similar units (e.g. student achievement scores for particular grade and school). Interrupted time series analysis requires knowing the specific point in the series when an intervention occurred.

A) CONFOUNDERS

By definition, a confounder is a variable that is associated with the intervention or exposure and causally related to the outcome of interest. Even in a robust study design, groups may not be balanced with respect to important variables prior to the intervention. The authors should indicate if confounders were controlled in the design (by stratification or matching) or in the analysis. If the allocation to intervention and control groups is randomized, the authors must report that the groups were balanced at baseline with respect to confounders (either in the text or a table).

B) BLINDING

(Q1) Assessors should be described as blinded to which participants were in the control and intervention groups. The purpose of blinding the outcome assessors (who might also be the care providers) is to protect against detection bias.

(Q2) Study participants should not be aware of (i.e. blinded to) the research question. The purpose of blinding the participants is to protect against reporting bias.

A) DATA COLLECTION METHODS

Tools for primary outcome measures must be described as reliable and valid. If 'face' validity or 'content' validity has been demonstrated, this is acceptable. Some sources from which data may be collected are described below:

Self reported data includes data that is collected from participants in the study (e.g. completing a questionnaire, survey, answering questions during an interview, etc.).

Assessment/Screening includes objective data that is retrieved by the researchers. (e.g. observations by investigators).

Medical Records/Vital Statistics refers to the types of formal records used for the extraction of the data.

Reliability and validity can be reported in the study or in a separate study. For example, some standard assessment tools have known reliability and validity.

B) WITHDRAWALS AND DROP-OUTS

Score **YES** if the authors describe BOTH the numbers and reasons for withdrawals and drop-outs.

Score **NO** if either the numbers or reasons for withdrawals and drop-outs are not reported.

The percentage of participants completing the study refers to the % of subjects remaining in the study at the final data collection period in all groups (i.e. control and intervention groups).

C) INTERVENTION INTEGRITY

The number of participants receiving the intended intervention should be noted (consider both frequency and intensity). For example, the authors may have reported that at least 80 percent of the participants received the complete intervention. The authors should describe a method of measuring if the intervention was provided to all participants the same way. As well, the authors should indicate if subjects received an unintended intervention that may have influenced the outcomes. For example, co-intervention occurs when the study group receives an additional intervention (other than that intended). In this case, it is possible that the effect of the intervention may be over-estimated.

Contamination refers to situations where the control group accidentally receives the study intervention. This could result in an under-estimation of the impact of the intervention.

D) ANALYSIS APPROPRIATE TO QUESTION

Was the quantitative analysis appropriate to the research question being asked?

An intention-to-treat analysis is one in which all the participants in a trial are analyzed according to the intervention to which they were allocated, whether they received it or not. Intention-to-treat analyses are favoured in assessments of effectiveness as they mirror the noncompliance and treatment changes that are likely to occur when the intervention is used in practice, and because of the risk of attrition bias when participants are excluded from the analysis.

Component Ratings of Study:

For each of the six components A–F, use the following descriptions as a roadmap.

A) SELECTION BIAS

Strong: The selected individuals are very likely to be representative of the target population (Q1 is 1) **and** there is greater than 80% participation (Q2 is 1).

Moderate: The selected individuals are at least somewhat likely to be representative of the target population (Q1 is 1 or 2); **and** there is 60–79% participation (Q2 is 2). ‘Moderate’ may also be assigned if Q1 is 1 or 2 and Q2 is 5 (can’t tell).

Weak: The selected individuals are not likely to be representative of the target population (Q1 is 3); **or** there is less than 60% participation (Q2 is 3) **or** selection is not described (Q1 is 4); **and** the level of participation is not described (Q2 is 5).

B) DESIGN

Strong: will be assigned to those articles that described RCTs and CCTs.

Moderate: will be assigned to those that described a cohort analytic study, a case control study, a cohort design, or an interrupted time series.

Weak: will be assigned to those that used any other method or did not state the method used.

C) CONFOUNDERS

Strong: will be assigned to those articles that controlled for at least 80% of relevant confounders (Q1 is 2); **or** (Q2 is 1).

Moderate: will be given to those studies that controlled for 60–79% of relevant confounders (Q1 is 1) **and** (Q2 is 2).

Weak: will be assigned when less than 60% of relevant confounders were controlled (Q1 is 1) **and** (Q2 is 3) **or** control of confounders was not described (Q1 is 3) **and** (Q2 is 4).

D) BLINDING

Strong: The outcome assessor is not aware of the intervention status of participants (Q1 is 2); **and** the study participants are not aware of the research question (Q2 is 2).

Moderate: The outcome assessor is not aware of the intervention status of participants (Q1 is 2); **or** the study participants are not aware of the research question (Q2 is 2); **or** blinding is not described (Q1 is 3 and Q2 is 3).

Weak: The outcome assessor is aware of the intervention status of participants (Q1 is 1); **and** the study participants are aware of the research question (Q2 is 1).

E) DATA COLLECTION METHODS

Strong: The data collection tools have been shown to be valid (Q1 is 1); **and** the data collection tools have been shown to be reliable (Q2 is 1).

Moderate: The data collection tools have been shown to be valid (Q1 is 1); **and** the data collection tools have not been shown to be reliable (Q2 is 2) **or** reliability is not described (Q2 is 3).

Weak: The data collection tools have not been shown to be valid (Q1 is 2) **or** both reliability and validity are not described (Q1 is 3 and Q2 is 3).

F) WITHDRAWALS AND DROP-OUTS - a rating of:

Strong: will be assigned when the follow-up rate is 80% or greater (Q2 is 1).

Moderate: will be assigned when the follow-up rate is 60–79% (Q2 is 2) **OR** Q2 is 5 (N/A).

Weak: will be assigned when a follow-up rate is less than 60% (Q2 is 3) or if the withdrawals and drop-outs were not described (Q2 is 4).

Empirical Study:

Modelling the interplay between childhood adversity, recent stressful life events and perceived social support in pathways to an 'ultra-high risk' (UHR) of developing psychosis

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Abstract

Childhood adversity and stress have repeatedly been related to psychosis risk. There is also strong evidence that individuals with a long-standing psychotic disorder have reduced social support relative to healthy comparison groups, although there is less research on the extent of social support prior to or at the onset of psychosis. In light of the evidence implicating a range of social experiences and contexts at the onset of psychosis, the present study aimed to establish whether perceived social support diminishes before the time of illness onset and whether the absence of perceived support contributes to risk, either directly or indirectly via connections with childhood adversity and recent stressful life events.

Eighty-one ultra-high risk (UHR) participants were recruited through a community service for people at UHR of psychosis. Sixty healthy control (HC) participants were recruited from the same geographical area. UHR and HC participants were compared on measures of perceived social support and the relationship between these measures and current symptoms was investigated. Structural equation modelling using latent variables of the data was then performed to assess whether the pathway from recent and lifetime adverse and stressful life events to current attenuated psychotic symptoms is mediated by perceived social support.

UHR participants reported less perceived availability of social support than HC participants, and UHR participants were more dissatisfied with the emotional support they received from others than HC participants. Perceived availability of practical and emotional support was associated with symptoms. In UHR participants, perceived availability of support from friends and significant others was associated with attenuated psychotic symptoms, but perceived availability of support from family members was associated with depressive symptoms only. No associations between satisfaction with social support and symptoms were found in UHR participants, but satisfaction with emotional support was negatively correlated with symptoms in HC participants. No evidence of mediation was found.

The results of this thesis demonstrate that reduced perceived social support pre-dates onset of psychosis. Implications for clinical interventions are suggested.

Table of Contents

Introduction	61
Ultra High Risk for Psychosis	61
Childhood adversity and Ultra High Risk for Psychosis.....	63
Recent stressful life events and Ultra High Risk for Psychosis.....	66
Social networks and social support and Ultra High Risk for Psychosis	69
Social factors in pathways to psychosis	71
Meditation analysis with Structural Equation Modelling (SEM).....	72
Mediation analysis	72
SEM and its advantages to standard regression methods for mediation analysis	73
Aims.....	75
Hypotheses.....	75
 Method	 76
Participants and Recruitment	76
Setting	76
Participants at ultra-high risk (UHR) of developing psychosis.....	77
Healthy control (HR) participants	77
Data Collection	78
Assessment of current symptoms.....	78
Assessment of early adverse and traumatic experiences.....	78
Assessment of recent adverse experiences	79
Assessment of perceived social support.....	79
Ethical Approval	80
Data Analysis	80
 Results	 83
Stage 1 - Perceived Social Support.....	84
Group Differences	84
Associations with symptoms.....	85
Stage 2 - Mediation Analysis	88

Mediation 1	88
Mediation 2	89
Discussion	92
Summary of main findings	92
Discussion of findings in relation to previous research	94
Clinical Implications.....	97
Recommendations for future research.....	99
Methodological Limitations	103
Conclusion	107
References	108
Appendices	126
Appendix 1: PACE criteria for identification of the UHR of psychosis status	126
Appendix 2: Participant Information and Consent Form.....	127
Appendix 3: Assessment measures and their coding procedure	131
3.1 The Prodromal Questionnaire (PQ)	131
3.2 The Beck Depression Inventory – 2 nd edition (BDI-II)	137
3.3 The Childhood Experience of Care and Abuse Questionnaire (CECA-Q)	139
3.4 The Retrospective Bullying Questionnaire (RBQ)	148
3.5 The Brief Life Event Questionnaire (BLEQ)	154
3.6 The Perceived Stress Scale (PSS)	159
3.7 The Multidimensional Scale of Perceived Social Support (MSPSS)	160
3.8 The Significant Other Scale (SOS).....	162
3.9 Coding Procedure.....	164
Appendix 4: Ethical Approval	172

List of Figures and Tables

Figure 1 Multiple Mediation Model.....	72
Figure 2 Path diagram dependent variable through the mediator variable.	73
Figure 3 Multiple Mediation Model with indicators for latent variables.	82
Figure 4 Mediation Model(s)	91
Figure 5 The Stress-Strain-Coping-Support (SSCS) model	101
Figure 6 Adaptation of the SSCS to psychosis risk factors	101
Table 1 Demographic characteristics of the sample.....	84
Table 2 Correlations between social support measrues and symptom scores for UHR participants	86
Table 3 Correlations between social support measures and symptom scores for HC participants.	87
Table 4 Correlations between indicators for latent variables.....	90
Table 5 Mediation Models: direct, indirect and total effects.....	92

Introduction

Childhood adversity and recent stressful life events have repeatedly been related to psychosis risk. Similarly, there is strong evidence that those with a long-standing psychotic disorder have fewer social relationships and support than comparison groups, although there is less research on the extent of social support prior to the onset of psychosis. In the light of this evidence implicating a range of social experiences and contexts at the onset of psychosis, the study presented in this thesis aims to establish whether perceived social support diminished before the time of psychosis onset and whether the absence of such support contributes to risk of onset, either directly or indirectly via connections with childhood adversity and recent stressful life events.

Ultra High Risk for Psychosis

Psychosis is a mental state characterised by a loss of contact with reality. This can manifest in a variety of ways, but most commonly as unfounded beliefs and ideas, perceptual abnormalities and hallucinations, and disorganised thoughts and speech (American Psychiatric Association, 2013). It is a key feature of several severe mental disorders, such as schizophrenia, bipolar disorder with psychotic features, and psychotic depression, all of which can be highly distressing for those experiencing them. Psychotic disorders are estimated to affect between 0.4 and 2.0 per cent of the UK population (Saha, et al 2005), and their onset usually occurs during late adolescence and early adulthood (Lieberman & Fenton, 2000).

Recent developments in psychosis research have indicated that psychosis exists on a continuum, ranging from sub-clinical psychosis-like experiences through to clinically relevant disorder (e.g. van Os et al, 2000; 2009). High prevalence rates of psychotic-like experiences have been reported in the general population (i.e. 7.2%-17.5%; van Os et al, 2000), and these have been found to be qualitatively similar and associated with the same demographic risk factors as those found in psychotic disorder (Linscott & van Os, 2013). While the majority of people reporting psychotic-like experiences do not go on to develop problems that interfere with their life or require clinical intervention (van

Os et al, 2009), for some individuals these psychosis-like experiences may gradually increase in severity and frequency and become associated with distress, particularly in the context of mood and anxiety disturbances (e.g. Fusar-Poli et al, 2013). Such experiences are known as attenuated psychotic symptoms and are associated with high risk of subsequent development of psychosis (Young et al, 2003). Other individuals at high risk for psychosis experience brief periods of frank psychotic symptoms, which would exceed diagnostic thresholds for psychosis, but remit spontaneously and without pharmacological intervention. Such periods are known as episodes of Brief Limited Intermittent Psychosis (BLIPs; Young et al, 2003). Individuals with schizotypal personality disorder or a family history of psychosis also have an increased risk for psychosis in the form of trait vulnerability and this risk has been found to be potentiated in the context of difficulties in social and occupational functioning (Young et al, 2004).

On the basis of these trait and state vulnerability characteristics Young and colleagues (1996; 2004) developed the Personal Assessment and Crisis Evaluation (PACE; see Appendix 1) criteria for identifying individuals at high risk of developing psychosis: Individuals who present with either 1) attenuated psychotic symptoms, 2) BLIPs, or 3) trait vulnerability coupled with a recent decline in socio-occupational functioning. Fulfilling PACE criteria indicates that an individual is at high risk of imminent psychosis onset, and these individuals are therefore considered to be at 'ultra high risk' (UHR) for psychosis. Individuals at UHR for psychosis represent a sub-population in the pre-clinical (or prodromal) phase of illness (i.e. those between clinical and non-clinical populations), which can last from months to years before the first episode of psychosis. These individuals experience frequent, severe and/or impairing psychotic-like experiences which indicate a need for care, however, which are at sub-threshold for clinical diagnosis.

Validity of the UHR construct has been evidenced by findings indicating several similarities between UHR and psychosis disorder groups, such as personality traits and neurocognitive deficits (although the latter feature in an mitigated form in UHR

individuals (Fresan et al, 2015). In addition, studies which have employed the UHR criteria to identify people at high risk for psychosis have reported rates of transition to psychosis over 12 to 14 months, which range from 10 to 50 per cent (Cannon, et al., 2007; Young et al, 2004). Thus, identifying people at an early stage (i.e. at UHR and before psychosis onset), as well as specific subgroups of individuals at UHR for psychosis who will or will not go on to transition to psychosis, provides opportunity both to determine indicators of extreme vulnerability and to employ interventions which may delay or prevent illness onset and prevent the need for exposure to interventions with more harmful side effects (McGorry, et al., 2006).

While a variety of terms (such as 'prodromal', 'at risk mental state' and 'at clinical risk') have been used in the literature to describe individuals who have been identified as being at high risk for psychosis, the term UHR was chosen for this study and is used throughout the remaining of this thesis.

Childhood adversity and Ultra High Risk for Psychosis

High prevalence rates of a history of childhood adversity, including physical and sexual abuse, are commonly reported in people diagnosed with psychotic disorders compared to the general population (Schaefer and Fisher, 2011; Bebbington et al., 2011; Aas et al., 2011; Husted et al., 2012), although whether or not such experiences constitute a causal risk factor for psychosis is still a matter of debate (Bendall, et al., 2008b; Morgan & Fisher, 2007). In their recent meta-analysis examining both retrospective and prospective studies, Varese and colleagues (2012) found that experience of childhood adversity and trauma increased the risk of psychotic disorder in adults with an odds ratio of 2.7, and a number of studies have elaborated on this finding (e.g. Kelleher, et al, 2013; Matheson et al, 2013). The mechanisms underlying this association are not yet fully understood. However, the predominant view is that an increased sensitivity to environmental stressors may be involved (Holtzman, et al, 2013). In line with the stress-vulnerability model (Myin-Germeys, et al, 2005a; Myin-Germeys, et al, 2001), development of psychotic symptoms is considered a function of both exposure to adverse life events (i.e. current stressor) and a type of trait

vulnerability to stressors. This may further be thought of as interactions early in the developmental trajectory between environment and genetic factors, resulting in stress sensitisation (Myin-Germeys and van Os, 2007).

While the investigation of childhood adversity and psychosis has targeted people with an established diagnosis of psychosis and the general population, fewer studies have addressed childhood adversity in individuals at UHR of developing psychosis. Two studies examined the relationship between childhood trauma and transition to psychotic disorder prospectively (Bechdolf et al., 2010; Thompson et al., 2010). In examining the impact of physical, sexual and emotional trauma on transition to psychosis in UHR individuals, both studies found that sexual trauma was specifically predictive of a first psychotic episode. In further examination of the 'sexual trauma' group, these individuals also presented more frequently with attenuated symptoms comprising possible sexual abuse content (Thompson et al., 2010). Three further studies investigated the relationship between previous trauma and symptom presentation in an UHR group (Thompson et al., 2009; Addington et al., 2013; Velthorst et al., 2013). Thompson and colleagues (2009) found that among 30 UHR individuals, 79% had experienced at least one type of trauma prior to entry to a clinic. Previous trauma was significantly related to reports of positive symptoms in individuals from ethnic minority groups and to affective symptoms among Caucasians, although interpretation of these results requires caution due to the relatively small sample size of the study and the absence of a geographically matched control group. Nevertheless, results were comparable in a more recent study of 360 individuals at UHR of developing psychosis and 180 age-and gender-matched healthy controls (Addington et al., 2013). Addington and colleagues (2013) found that UHR individuals reported significantly more early traumatic experiences and bullying than health controls. Individuals who experienced past trauma and bullying were also more likely to have increased levels of depression and anxiety, and poorer sense of self. Similarly, Velthorst and colleagues (2013) reported that in a sample of 127 UHR individuals, 56% had experienced at least one type of previous trauma. Examining baseline differences in intensity, form and content of attenuated positive symptoms, other clinical

symptomatology and comorbidity between the UHR individuals with and without a history of trauma, the authors found that intensity of perceptual abnormalities was significantly higher in the UHR group with a history of physical abuse compared to the UHR group without a trauma history. Physical abuse was further related to high levels of visual disturbances, suspiciousness, grandiose beliefs and low mood. Sexual trauma was related to perceptual disturbances with abusive content and PTSD symptoms. The results of a recent meta-analysis that reviewed existing evidence on the prevalence of childhood trauma in UHR individuals (Kraan et al., 2015) showed that childhood trauma rates in UHR populations are high, and substantially higher than rates in the general population (ranging from 42.7 to 60%) (Addington et al, 2013; Tikka et al., 2013). The reported mean prevalence rate of 86.8% for a history of trauma is consistent with the reported prevalence rate of 85% in individuals with an established diagnosis of schizophrenia (Larsson et al., 2013). Thus, although few in nature, these studies provide further support for early adversity as a risk factor for psychosis.

Results from recent unpublished work by the OASIS research group (Day, 2012) further support previous research findings. The study revealed high prevalence of early adverse or traumatic experiences in UHR individuals, with UHR individuals having experienced significantly more early adverse or traumatic experiences than HC participants. Moreover, UHR individuals were significantly more likely to have experienced abuse and trauma while growing up than HC participants. Rates of exposure to physical abuse, sexual abuse, emotional abuse and loss of or separation from a parental figure were consistently higher in the UHR individuals, although only group differences in prolonged maternal separation and emotional abuse from the mother figure reached statistical significance. UHR individuals were found to be nine times more likely to have experienced prolonged separation from their mother while growing up than HC participants. In addition, high rates of victimization at school were reported UHR individuals; UHR individuals were found to be twice as likely as HC participants to report experiences of severe physical, verbal, or indirect bullying during their secondary education. While the increased exposure to childhood adverse and

traumatic events in the UHR individuals in this study is consistent with previous research, it is to note that no association between overall exposure to early adversity and current attenuated psychotic symptoms was found. Although the study may have lacked sufficient power to detect this association.

Recent stressful life events and Ultra High Risk for Psychosis

An understanding of the potential role of stress in the development of psychosis might be important in the refinement of psychological interventions aimed at recovery and prevention (Myin-Germeys et al, 2005a). Several studies have reported that individuals with psychosis experienced more stressful life events in the period leading up to a psychotic episode (Brown & Birley, 1968; Bebbington, et al., 1993; Canton & Fraccon, 1985; Chaven & Kulhara, 1988; Day, et al., 1987; Jacobs & Myers, 1976; Mazure, et al., 1997; Michaux, et al., 1967; Mondelli, et al., 2010a; Pallanti, et al., 1997; Schwartz & Myers, 1977; Ventura, et al., 1989), suggesting that stressful life events might serve to precipitate the emergence of psychotic symptoms. However, these findings have not been replicated in all studies (Chung, et al., 1986; Gruen & Baron, 1984; Hirsch, et al., 1996), and varied depending on gender (Al Khani, et al., 1986).

Previous studies that have sought to investigate a potential relationship between recent stressful life events and the onset of psychosis have been hampered by methodological limitations, such as retrospective design, small sample size, and inappropriate comparison groups (Phillips et al., 2007a, 2009b). Critically, the majority of previous studies have simply assessed the number of events an individual has experienced (Phillips et al., 2007a). There has also been criticism of the heterogeneity of the samples in terms of stage of psychotic disorder and the definition of a stressful life event. These limitations have made it difficult to determine the role of recent stressful life events in the onset of psychosis, and recent studies suggest that stressful life events may be more relevant to relapse in established psychosis than the development of the first psychotic episode (Nuechterlein, et al., 1989; Pallanti, et al., 1997).

There is also great variation across studies in which events and experiences are considered life events and over what time period such events are assessed (Phillips, et al., 2007a). Malla and Norman (1992) reported that it was the number of minor stressors, rather than life events, experienced by people with schizophrenia that correlated with their level of distress, suggesting that it is chronic exposure to everyday stress that might be more relevant to psychotic symptoms than major stressful events (Norman & Malla, 1993a). This is supported by research showing that sensitivity to stress is increased in people with psychosis, such that greater emotional and behavioural reactivity to small stressors encountered in daily life is observed in people with psychosis (Myin-Germeys, et al., 2005a; Myin-Germeys, et al., 2001). This is manifested as greater increases in negative affect and decreases in positive affect, as well as greater intensity of psychotic symptoms. This heightened responsivity to stress is also present in people who have a genetic predisposition for psychosis, which suggests that vulnerability to psychosis might be manifested in subtle changes in the way people respond to stressful events (Myin-Germeys & van Os, 2007). Furthermore, it has been suggested that repeated or chronic exposure to traumatic or stressful experiences throughout the lifetime may result in a lowered tolerance threshold for subsequent stressors, in other words, stress sensitivity, such that minor hassles may have a greater impact on mental state (Read, et al., 2001; van Winkel, et al., 2008b).

To date, three studies have investigated recent stressful life events and daily hassles in UHR groups and they do not provide support for a role of such stressors in either expression of psychotic symptoms or subsequent transition to psychosis. Experience of recent stressful experiences in a sample of 74 UHR participants was not associated with the development of psychosis (Mason, et al., 2004), and life events did not appear to be related to symptomatology in a smaller sample (n=13, Thompson, et al., 2007b). A significant correlation was found between the number of hassles experienced by 18 UHR participants and scores on the Brief Psychiatric Rating Scale, but no association was found with the positive symptom subscale, which suggests that any effect may be nonspecific, although the sample size in this case was small (Thompson, et al., 2007b). A longitudinal study comparing the experience of stress between UHR individuals and

healthy controls found that UHR individuals experienced significantly fewer life events over the previous twelve months than healthy controls, although UHR individuals reported feeling significantly more distressed by these events. No differences in the experiences of minor events were reported (Phillips, et al., 2012). Similarly, in a large sample (n=115) of individuals at genetic high-risk of psychosis (Miller, et al., 2001) no differences in the number of major life events experienced by the high-risk group and two comparison groups (healthy controls and first episode psychosis patients) were found, and the experience of 'intermediate' or 'minor' stressors was not associated with symptom levels.

In contrast to previous research, results from unpublished work by the OASIS research group (Day, 2012) showed that UHR individuals were more likely to have experienced a recent stressful life event than healthy control participants, and that UHR individuals had experienced more recent stressful experiences than HR participants. There was also a significant group difference in the level of current perceived stress; UHR individuals reported higher levels of current perceived stress than HC participants. Moreover, results from this study revealed that both the number of recent stressful experiences and the current level of perceived stress were significant predictors of current attenuated psychotic symptoms in the UHR individuals.

A possible explanation for the discrepancies in findings between research studies might be that UHR populations are too heterogeneous to detect the relationship between psychosis and stressful life events. Alternatively, it may be that in order to detect a significant relationship in heterogeneous UHR samples, studies need to address the combination of both childhood adversity and recent stressful life events. It is not unlikely that a combination of these two factors causes a 'double-hit reaction' where childhood adversity leads to a general sensitivity to stress, and a stressful life event later in life may then cause an individual to eventually cross the psychosis threshold.

Social networks and social support and Ultra High Risk for Psychosis

The relationship between social relationships and health has long been recognized (e.g. Cohen & Willis, 1985; Thoits, 2011). Good social relationships and social support tend to be associated with better physical and mental health and with a longer lifespan (Holt-Lunstand, Birmingham, & Jones, 2008). Conversely, dysfunctional social networks and low social support have been associated with poorer physical and mental health, and poorer treatment outcomes than those with functioning social networks and good social support (Greenblatt et al, 1982).

Over the past four decades researchers have tried to define and describe the quantitative and qualitative characteristics of social networks and social support that appear to be responsible for these protective functions. Social networks are a subset of the totality of social contacts. They are defined by persistence over time and a degree of significance, and are held to play an important role in the maintenance of the psychological and physical integrity of a person. Primary relationships are distinguished from less personal secondary relationships (Cresswell et al, 1992). Social networks can be specified further in terms of structural and functional aspects. Functional aspects refer to what is provided by, or perceived to be available from social relationships, whereas structural aspects refer to the existence and pattern of interactions of network members rather than the content or quality of relationships (Hammer, 1981). Social networks can also be described in terms of quantitative and qualitative aspects. Quantitative aspects include density and size of the network, kin vs. non-kin composition, marital status and living alone vs. living with others. Qualitative aspects refer to an individual's degree of satisfaction with their social relationships. This includes reciprocity (the extent to which the relationship is characterized by giving as well as receiving), accessibility (the ease with which network members can be contacted), multiplexity (the number of separate functions provided by relationships), social isolation (pervasive lack of social contact or communication), the presence or absence of a confidant (someone who provides a relationship characterized by emotional intensity, reciprocity and availability), and loneliness.

Social networks are important because they are the vehicle for delivering social support. However, support does not map perfectly onto the attributes of social networks. For example, someone with a large social network may actually feel lonely. More precisely, social support can be conceptualized as the functional aspects of social relationships. The most frequently mentioned functions of supportive behaviours are emotional, informational and instrumental support (Alloway & Bebbington, 1987; Thoits, 2011). Social support is a complex construct, which consist of several sub-constructs (Heller & Swindle, 1983). The most commonly distinguished constructs are received and perceived support. Received social support refers to the provision of supportive behaviour from others, while perceived social support refers to the recipients' perception of the availability of support and their satisfaction with it (Sarason & Sarason, 2009). The main difference between the two constructs is that perceived social support refers to the anticipating help in times of need, whereas received social support refers to recalling previously received support in a given time period (Ibarra-Rovillard & Kuiper, 2011). This distinction is important because research has consistently shown stronger links between health and perceived social support (Ibarra-Rovillard & Kuiper, 2011).

People with severe mental health problems, such as psychosis, commonly struggle to develop and maintain functioning relationships and tend to miss out on good social support (e.g. Norman et al, 2005). Social relationships and social support deficits characteristic of psychosis are already apparent in the very early stages of the disorder (Gayer-Anderson & Morgan, 2012). Even at first episode, the social networks of people with psychosis comprise fewer members, with whom they may have little contact. In addition, their networks tend to contain proportionately more family members, they have fewer confidants, and more people are described as acquaintances (Morgan et al, 2008). They are also less likely to be satisfied with the level of support they receive, despite receiving more than they give (i.e. despite non-reciprocity).

To date, two studies examined social relationships and social support in a sample of people at UHR of developing psychosis (Willhite et al, 2008; Preussner et al, 2011).

Willhite and colleagues (2008) investigated gender differences in UHR individuals and found that females reported higher levels of social support than males, although this study did not include a control group. In a more recent study, Pruessner and colleagues (2011) examined stress and psychological factors in individuals with an UHR of developing psychosis, first episode patients and healthy controls. Both UHR individuals and first episode patients had lower perceived social support and active coping than controls, therefore further adding to the notion that poor social networks and support are already present at illness onset.

Social factors in pathways to psychosis

Substantial evidence has accumulated over the past decade linking various social factors (e.g. communication deviance of caregivers, childhood traumas and adversity, disadvantage, migration, socio-economic status, exposure to urban environments, and ethnicity) with both psychotic disorders and psychotic experiences in the general population (e.g. de Sousa et al, 2013; Morgan et al., 2008, van Dam et al, 2012; Varese et al, 2012; Vassos et al, 2012). However, studies that have implicated such factors have tended to consider each exposure separately. This is despite the fact that social adversities and disadvantages tend to cluster in individuals, families and neighbourhoods, persist over time, and are often associated with poor outcomes in a number of domains (e.g. education, health, housing) which in turn further amplify disadvantage and thus create for many a vicious cycle (Pantazis et al, 2006). In addition, most aetiological theories imply co-participation of a number of risk factors (Morgan et al, 2014).

Modelling the interplay between social support and already known psychosis risk factors, such as childhood adversity and recent stressful life events, could further contribute to our knowledge about possible pathways to psychosis. There are a number of ways in which social factors might relate to each other in pathways to psychosis. Some social factors may impact on risk indirectly by increasing likelihood of exposure to more proximal risk factors. For example, childhood adversity may link to psychosis, in part, via increasing vulnerability to experiencing further adverse or

stressful life events (Morgan et al., 2014), such that childhood adversity is an early step on a causal path (i.e. mediation model). Social factors may also combine to increase risk. That is, the impact of exposure to two or more factors may be greater than the sum of the individual effects alone (i.e. multiple mediation). To the best of the author's knowledge, no studies to date have examined mediation or multiple mediation analysis including combinations between social support and recent and lifetime adverse and stressful life events in relation to psychosis. Assessment of this model (see Figure 1) is one way to expand the standard approach beyond identification of single risk factors.

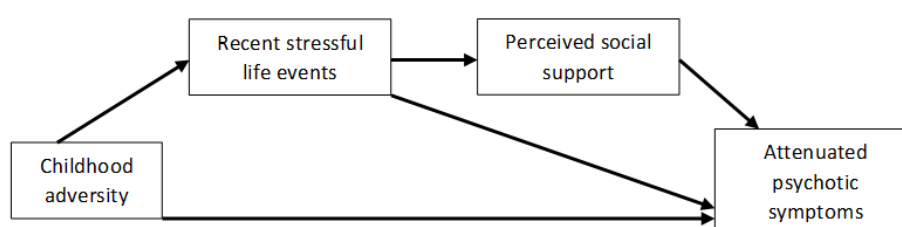


Figure 1 Multiple Mediation Model: The effect of recent and lifetime stressful and adverse events on symptoms via perceived social support.

Meditation analysis with Structural Equation Modelling (SEM)

Mediation analysis

Mediation is a hypothesised causal chain in which the effect of an independent variable (X) on a dependent or outcome variable (Y) is transmitted through a mediating variable (M). That is, X causes M, and M causes Y. Figure 2 illustrates the path diagrams for a simple mediation model. The top diagram in figure 2 below represents the *total effect* of X and Y and the bottom diagram represents the *indirect effect* of X on Y through M and the *direct effect* of X on Y controlling for M. If the mediator M explains the correlation between X and Y, a full mediation exists. If X still has an effect on Y after including the mediator M in the model, the model is consistent with partial mediation.

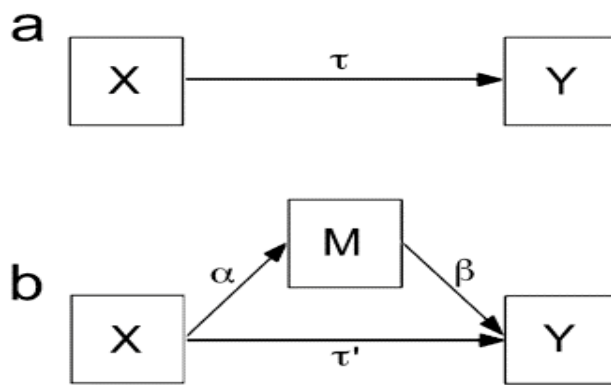


Figure 2 Path diagram for (a) the total effect of the independent variable on the dependent variable and (b) the indirect effect of the independent variable on the dependent variable through the mediator variable.

Structural equation modelling (SEM) and its advantages to standard regression methods for mediation analysis

Structural equation modelling (SEM) is a very powerful multivariate technique. It uses a conceptual model, path diagram and system of linked regression-style equations to capture complex and dynamic relationships within a web of observed and unobserved variables. Although similar in appearance, SEM is different from regression (Gunzler et al, 2013). A regression model is a subset of a path model. SEM extends path analyses by modelling the relationship of latent variables (or constructs). Latent variables allow the measurement of unobservable abstract psychological variables which cannot be measured directly, but only inferred from the observed measured variables. An advantage of SEM is that the use of latent variables takes measurement error of the observed measured variables into account.

SEM consists of two parts: a *measurement model* and a *structural model*. The structural model deals with the relationship between the latent variables while the measurement model describes the relationship between the observed measured variables and the latent variables. SEM models are best represented by path diagrams. An SEM path diagram consists of nodes representing the variables and arrows showing relationships among these variables. By convention, in a path diagram latent variables (e.g. stress) are represented by circle or ellipse and observed variables (e.g. a score on a rating scale) are represented by a rectangle or square. Arrows are generally used to

represent relationships among the variables, and a single straight arrow indicates a causal relationship from the base of the arrow to the head of the arrow. Several SEM-specific software packages are available to perform SEM analyses. For example, Mplus is a statistical modelling program that offers researchers a wide choice of models, estimators, and algorithms in a program that has a relatively easy-to-use interface and graphical displays of data and analysis results. Mplus further allows the analysis of both cross-sectional and longitudinal data, single-level and multilevel data, data that come from different populations with either observed or unobserved heterogeneity, and data that contain missing values. Finally, In Mplus analyses can be carried out for observed variables that are continuous, censored, binary, ordered categorical (ordinal), unordered categorical (nominal), counts, or combinations of these variable types (Muthén & Muthén, 1998-2014).

There are multiple advantages to using the SEM framework in the context of mediation analysis. When a model contains latent variables such as stress, SEM allows for ease of interpretation and estimation. SEM simplifies testing of mediation hypotheses because it is designed, in part, to test these more complicated mediation models in a single analysis. SEM can be used when extending a mediation process to multiple independent variables, mediators or outcomes. This contrasts with standard regression, in which ad hoc methods must be used for inference about indirect and total effects (Baron & Kenny, 1986; Sobel, 1982; Clogg et al, 1992). These ad hoc methods rely on combining the results of two or more equations to derive the asymptotic variance. This is especially problematic when there are different numbers of observations missing in the different regression equations representing a mediation process. Also, in standard regression, we handle missing data via listwise deletion since there is no built-in missing data mechanism when using ordinal least squares (OLS). Another important advantage of SEM over standard regression methods is that the SEM analysis approach provides model fit information about the consistency of the hypothesized mediation model to the data and evidence for the plausibility of the causality assumptions made when constructing the mediation model (Bollen & Pearl, 2012; Imai et al, 2010). The standard regression procedure initially recommended by

Baron and Kenny (1986) has also been shown to be low powered (MacKinnon, 2008).

Aims

In the light of the above, the study presented in this thesis aims to extend previous analysis of unpublished work by the OASIS research group (Day, 2012), to examine whether social support (specifically perceived social support) diminishes before the time of psychosis onset and whether the absence of such support contributes to psychosis risk, either directly or indirectly via connections with childhood adversity and recent stressful life events. Specifically, this study aimed to test the hypothesis that exposure to adverse and stressful life events increase the risk of psychotic symptoms and that this link is mediated by perceived social support. Structural equation modelling using latent variables of the data will be conducted to assess the pathway from recent and lifetime adverse and stressful life events to current attenuated psychosis symptoms via perceived social support, and to examine full and partial mediation processes.

While the same data (on childhood adversity and recent stressful life events) as in unpublished work by the OASIS research group (Day, 2012) is used, the study presented in this thesis extends this work by inclusion and examination of a third variable (i.e. perceived social support), and by construction of a novel theoretical model that examines mediation between several social factors in relation to psychosis. This together with the use of a more powerful method of statistical analysis (i.e. SEM) enables expanding the standard approach beyond identification of single psychosis risk factors.

Hypotheses

In relation to the aims of this study and based on previous research in people with or at risk of psychosis, the following hypotheses were developed:

1. Perceived Social Support

1.1 Perceived social support will be reduced in UHR participants compared to HC participants.

1.2 Perceived social support will be associated with current attenuated psychotic symptoms.

2. Associations between recent and lifetime adverse life events, perceived social support and attenuated psychotic symptoms

2.1 In the UHR group, the association between recent and lifetime adverse and stressful experiences and attenuated psychotic symptoms will be mediated by perceived social support.

Method

Participants and Recruitment

Setting

All participants at ultra-high risk (UHR) of developing psychosis were recruited from the Outreach And Support In South London (OASIS) service (Fusar-Poli et al, 2012). OASIS provides support and treatment to young people aged between 14 and 35 years, who are considered to be at high risk of psychosis. The service was set up in 2001 and operates within South London, covering the boroughs of Lambeth and Southwark. OASIS operates an open referral system; the service accepts referrals from General Practitioners (GP), Community Mental Health Teams (CMHT), self-referrals, referrals from family members or friends, as well as referrals from schools, colleges, and voluntary community services. All suitable referrals are offered an assessment with a psychiatrist or clinical psychologist from OASIS, which includes an interview using the Comprehensive Assessment of At Risk Mental State (CAARMS, Young et al, 2005) to determine whether the individual meets the PEACE criteria (Young, et al, 2004; see Appendix 1) for being at ultra-high risk of developing psychosis.

Healthy control participants (HC), similar in distribution of the matching variables age, gender, and ethnicity, were recruited from the same geographical area as UHR participants (i.e., South London). All participants provided written informed consent before taking part in the study (see Appendix 2).

Participants at ultra-high risk (UHR) of developing psychosis

The following inclusion criteria were used to identify UHR participants eligible for participation in this study: 1) living within SLaM catchment area, 2) aged between 14-35 years old, and 3) meeting PACE criteria for an UHR of developing psychosis. Participants were excluded if they had: 1) a history of psychosis or experienced a current psychotic episode, 2) a Learning Disability, or 3) insufficient English language ability.

Out of 204 people who were assessed by OASIS and fulfilled ARMS criteria between June 2001 and December 2009, 133 individuals were considered eligible to be approached for participation. Where possible, these individuals were approached face to face. Alternatively, contact was made via telephone or letter. In total, 98 individuals provided consent to take part in the research presented in this study, and 90 of these took part in at least one aspect. As not all participants took part in all aspects of this study, the sample size varies and is described appropriately for each section.

Healthy control (HR) participants

Healthy control (HC) participants were recruited using a variety of methods: 1) People who had registered on the MindSearch research volunteer database (www.mindsearch.iop.kcl.ac.uk) were approached, 2) People who had previously taken part in research studies at the Institute of Psychiatry were approached, 3) Posters were put up in the local area, 4) A group on www.facebook.com was set up, and 5) Existing participants were asked to pass on details of the study to any friends that might be interested in taking part. The following inclusion criteria were used to identify HC participants eligible for participation in the study: 1) aged between 18 and 35 years

old, 2) living (or grown up) in south London, and 3) no personal history of mental health problems. Due to an over-representation of HC participants with degree-level education as recruitment progressed, a further inclusion criteria was introduced to appropriately match HC and UHR participants for education level; HC participants were required to have spent less than 13 years in education. In total, 60 individuals provided consent to take part in the research presented in this study, and 59 of these took part in at least one aspect. As not all participants took part in all aspects of the study, the sample size varies and is described appropriately for each section.

Data Collection

All data were collected between June 2001 and December 2009 by four research workers, as well as members of the OASIS clinical team. A brief description of the assessment measures used is provided below. For a copy and full description of all measures, as well as the procedure used to code items please refer to the Appendix 3).

Assessment of current symptoms

Participants completed the Prodromal Questionnaire (PQ; Loewy, et al., 2005) in order to assess current attenuated psychotic symptoms and the Beck Depression Inventory (BDI-II; Beck, et al., 1996) in order to assess current depressive symptoms. The PQ has demonstrated good construct validity with the SIPS in the UHR sample, with a score of eight or more positive symptoms predicting high risk status with 90 per cent sensitivity and 49 per cent specificity (see Loewy et al, 2005). Similarly, the BDI-II has been shown to demonstrate good reliability (average alpha coefficient around 0.9) and validity (r ranging from 0.82 to 0.94) in clinical and nonclinical samples (Kuehner et al, 2007). The primary proxies of the latent variable current symptoms, used in the mediation analysis of this study were: 1) total PQ negative subscale score; 2) total PQ disorganisation subscale score; and 3) total PQ general subscale score.

Assessment of early adverse and traumatic experiences

Exposure to early adverse or traumatic experiences was assessed using the Childhood Experience of Care and Abuse Questionnaire (CECA-Q; Bifulco, et al., 2005), which was

administered as a semi-structured interview, and the Retrospective Bullying Questionnaire (RBQ; Schafer, et al., 2004), which was administered as a self-report questionnaire. The RBQ and the CECA-Q have shown good reliability (average alpha coefficient around 0.8 for both the CECA-Q and the RBQ) and validity (r ranging from 0.48 to 0.66) as self-report measures for adverse childhood experience (Bifulco et al, 2005; Schaefer et al, 2004). The primary proxy of childhood adversity used in the mediation analysis of this study was the total early adversity score.

Assessment of recent adverse experiences

Exposure to recent adverse life events was assessed using the Brief Life Event Questionnaire (BLEQ; Brugha & Cragg, 1990). This questionnaire has been shown to have robust test–retest reliability (average alpha coefficient 0.8) and validity ($r = 0.7$), and it has been used in several previous studies (Brugha & Cragg 1990). The Perceived Stress Scale (PSS; Cohen & Williamson, 1988) was also used to assess current perceived stress. The PSS has shown good psychometric properties for clinical and non-clinical populations (reliability: average alpha coefficient > 0.7 ; validity: average $r > 0.7$; Lee, 2012). Both instruments were administered as self-report questionnaires. The following four proxies of the latent variable recent stressful life events were used in the mediation analysis of this study: 1) the total number of independent stressful life events (i.e. an event which is outside an individual's control or unlikely to be influenced by their actions) that occurred in the past six month; 2) the total number of dependent stressful life event (i.e. an event which is influenced by an individual's actions or within their control) that occurred in the past six month; 3) the total number of 'very bad' stressful life events (i.e. an event that was perceived by the individual as very bad) that occurred in the past six month; and 4) current perceived stress in form of the total PSS score.

Assessment of perceived social support

To assess social support, participants completed the Multidimensional Scale of Perceived Social Support (MSPSS; Zimet, et al., 1988) and the Significant Others Scale (SOS; Power, et al., 1988). The MSPSS measures perceived availability of social support

from family, friends, significant others, and overall, while the SOS measures perceived availability of, as well as satisfaction with the amount of emotional and practical support provided by three named significant others (typically partners, friends, significant other). Both measures have demonstrated good reliability (alpha coefficient ranging from 0.85 to 0.91 for the MSPSS and 0.73 to 0.83 for the SOS) and validity ($r = 0.7$ for both measures) in clinical and non-clinical samples (Zimet et al, 1990; Power et al, 1988). For the mediation analysis of this study, the latent variable perceived social support was operationalised as 1) perceived availability of social support from others (i.e. the perceived availability of social support from significant others; the perceived availability of social support from friends; and the perceived availability of social support from family members), and 2) perceived satisfaction with the social support provided by others (i.e. the perceived satisfaction with emotional support provided by others; and the perceived satisfaction with practical support provided by others).

Ethical Approval

This study was approved by the joint South London and Maudsley NHS Trust and Institute of Psychiatry Research Ethics Committee. Ethical approval for the original study “Cortisol in people with prodromal symptoms” was granted in 2003 (Study Number 013/03), and approval for the amended study “Psychological stress and the hypothalamic-pituitary-adrenal axis in people at ultra-high risk of developing psychosis” was granted in 2005 (see Appendix 4). As no additional data was collected for this study, no further ethical amendment was required.

Data Analysis

The analysis was conducted in two stages. In the first stage, differences in scores of perceived social support (i.e. in MSPSS and SOS scores) between groups (i.e. between UHR and HC participants), and associations between perceived social support scores and current symptoms were investigated. Chi-square tests and independent samples t-tests were used to investigate any differences in demographic variables between the two groups. Any group differences in the MSPSS scores were determined using independent samples t-test, while Mann-Whitney U-test was used to investigate group

differences in Significant Other Scale (SOS) scores, as these data were not normal distributed. Pearson correlation was used to investigate associations between total MSPSS scores, total MSPSS scores for each domains, and current symptoms within each group. Spearman correlation was used to investigate associations between total SOS scores and current symptoms, because these data were not normal distributed. These initial data analyses were carried out using the Statistical Package for Social Sciences version 22.0 (SPSS Institute, Chicago, IL, USA; www.spss.com).

In the second stage, structural equation modelling using latent variables of the data was performed to assess possible mediation within the UHR group (Judd & Kenny, 1981; Baron & Kenny, 1986; MacKinnon, 2008). This study assessed the pathway from recent and lifetime adverse and stressful life events to current attenuated psychosis symptoms via perceived social support, examining full and partial mediation processes (structural SEM model). Recent stressful life events, perceived social support and attenuated psychotic symptoms were modelled as latent variables. The indicators (i.e. observed variables) for the latent variable recent stressful life events were 1) the total number of independent stressful life events that occurred in the past six month; 2) the total number of dependent stressful life event that occurred in the past six month; 3) the total number of 'very bad' stressful life events that occurred in the past six month; and 4) current perceived stress in form of the total PSS score. The indicators for the latent variable perceived social support were 1) perceived availability of support from significant others; 2) perceived availability of support from friends; 3) perceived availability of support from family members; 4) perceived satisfaction with emotional support; and 5) perceived satisfaction with practical support. The indicators for the latent variable attenuated psychotic symptoms were 1) total PQ negative subscale score; 2) total PQ disorganisation subscale score; and 3) total PQ general subscale score. Figure 3 illustrates the mediation model with indicators for each latent variable.

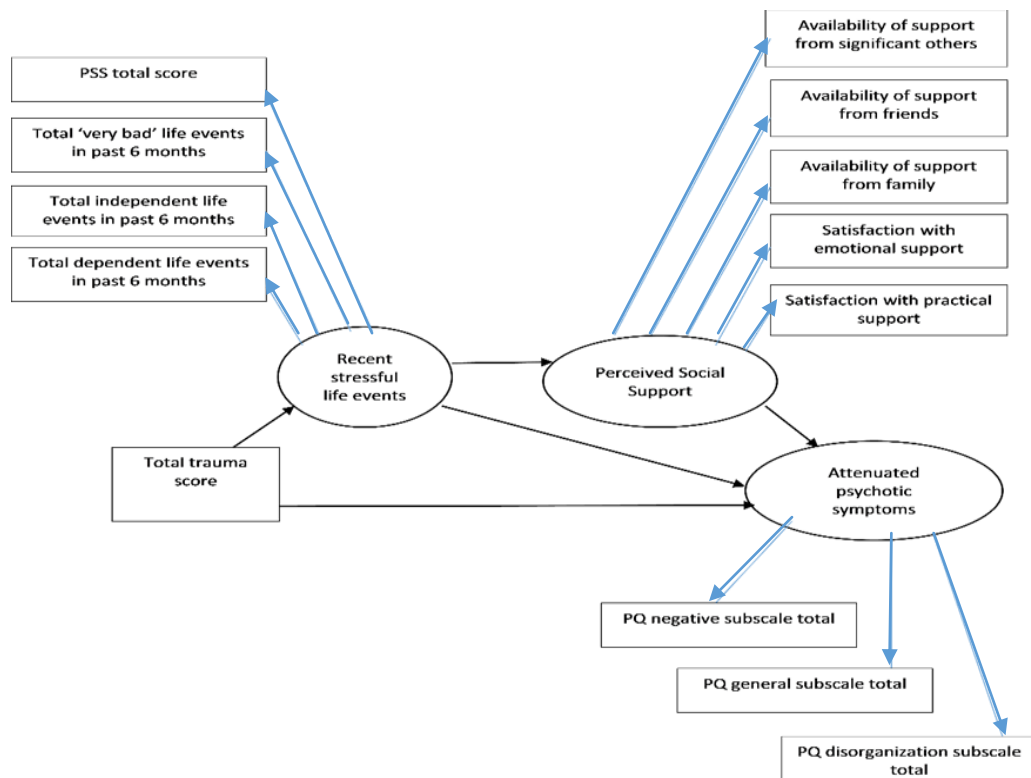


Figure 3 Multiple Mediation Model with indicators for latent variables.

Latent variables are represented by circles; indicators are represented by rectangles; arrows represent relationships.

A Confirmatory Factor Analysis (CFA) was performed initially to assess the goodness of fit of the measurement model (i.e. the relationship between indicators and latent variables) of the mediation models. Model fit of the mediation model and CFA models were assessed using the X^2 goodness-of-fit statistic and assessing the Comparative Fit Index (CFI), the Root Mean-Square-Error of Approximation (RMSEA) and the Standardized Root-Mean-Square Residual (SRMR). Support for good fit of a target mediation model is obtained if the X^2 goodness-of-fit test is not significant, the CFI value is >0.95 (adequate fit: >0.90), the RMSEA value is <0.05 (adequate fit: <0.06) and the SRMR value is <0.08 (Kline, 2004).

All mediation analysis used the robust weighted least squares means and variances adjusted estimator (WLSMV) to compute coefficients of probit models (categorical or ordinal outcomes), as this approach provides more accurate estimates of direct, indirect and total effects and allows for the use of bias-corrected bootstrapping (MacKinnon, 2008; Preacher & Hayes, 2008). Data were assumed to be missing at random, which

allows for inclusion of the full sample using WLSMV and maximum likelihood (ML) estimation. All mediation analysis was carried out using Mplus version 7.3 (Muthen & Muthen, 1998-2014).

Sample size calculation

Based on simulation studies a sample size of 71 of r would be sufficient to detect a medium mediation effect with 80% power at an alpha level of 0.05 (80 % power , 5% alpha level; see Fritz & MacKinnon, 2007).

In addition, this sample would be big enough to detect an effect size (correlation) of 0.31 of social support with attenuated psychotic symptom severity with 80% power at an alpha level of 0.05 (Cohen, 1969). A previous UHR study reporting similar analysis used a sample size of 30 to detect an observed effect size of 0.45 (Pruessner et al, 2011).

Results

The UHR and HC group were similar in distribution of matching key demographic characteristics age, gender, ethnicity, as well as country of birth and migration status. There were group differences in employment status and level of education, with unemployment being more common in UHR participants than HC participant (55.6% vs 6.7% respectively; $\chi^2 (2) = 37.2$; unadjusted $p < .001$), and with the HC participants having spent, on average, over a year longer in education than UHR participants (mean \pm SE: 15.0 \pm 0.3 years vs. 13.7 \pm 0.3 years respectively; $t (128) = -3.1$; unadjusted $p = .003$). UHR were also less likely than HC participants to have come from a 'middle class' background (52.5% vs 75.9%, respectively; $\chi^2 (1) = 6.8$; unadjusted $p = .009$). Table 1 shows the demographic characteristics of the sample.

Table 1 Demographic characteristics of the sample

		UHR (n=81)	HC (n=60)	Unadj. p
Age	Years, mean±SE	23.0±0.5	23.8±0.6	p=.262
Gender	% Male : Female	56.8 : 43.2	60.0 : 40.0	p=.702
Ethnicity	% White British	48.1	36.7	p=.411
	% Black	25.9	25.0	
	% White Other	11.2	18.3	
	% Other	14.8	20.0	
Born in UK	% UK : Non-UK	82.7 : 17.3	76.7 : 23.3	p=.373
Migration Status	% Non-migrant	60.8	55.0	p=.765
	% 1 st generation migrant	19.0	23.3	
	% 2 nd generation migrant	20.2	21.7	
Social Class	% ABC1 : C2DE	52.5 : 47.5	75.9 : 24.1	p=.009*
Occupation	% Unemployed	55.6	6.7	p<.001*
	% Student	21.0	35.0	
	% Employed	23.4	58.3	
Education	Years, mean±SE	13.7±0.3	15.0±0.3	p=.003*

ABC1, 'middle class'; C2DE, 'working class'; SE, Standard Error; Unadj., Unadjusted; %, percent. Significant correlations ($p<0.05$) are indicated by asterisks

Stage 1 - Perceived Social Support

Eighty-one UHR and 60 HC participants provided information on perceived social support; one UHR participant did not complete the full Multidimensional Scale of Perceived Social Support (MSPSS) scale, fourteen UHR and two HC participants did not complete the full Significant Other Scale (SOS).

Group Differences

UHR participants reported significantly less perceived availability of social support than HC participants on all support domains: from family members (means \pm SE: 15.6 \pm 6.7 vs. 21.1 \pm 5.6; $t(139) = -5.1$; $p<.001$), from friends (means \pm SE: 16.1 \pm 7.2 vs. 22.3 \pm 5.4; $t(138) = -5.6$; $p<.001$), from significant others (means \pm SE: 17.3 \pm 7.8 vs. 22.1 \pm 6.7; $t(139) = -3.8$; $p<.001$), and overall (means \pm SE: 49.2 \pm 17.9 vs. 65.6 \pm 14.8; $t(138) = -5.7$; $p<.001$). In addition, UHR participants reported receiving significantly less emotional support ($U = 1206$; $p<.001$; $r = -0.3$) as well as significantly less practical

support ($U = 1005$; $p < .001$; $r = -0.4$) from others than HC participants. Further to this, UHR participants reported significantly greater dissatisfaction with the amount of emotional support they received from others than HC participants ($U = 1501$; $p = 0.03$; $r = -0.2$). There was no difference in satisfaction with the amount of practical support provided by others between UHR and HC participants.

Associations with symptoms

One hundred and thirty-seven participants (78 UHR and 59 HC) completed the PQ and 128 participants (73 UHR and 55 HC) completed the BDI.

Correlations between perceived social support measures and current symptoms are presented in Table 2 for UHR participants and in Table 3 for HC participants. In the UHR group, negative correlations were found between perceived availability of social support and current depressive symptoms for all support domains. Similarly, in the UHR group negative correlations were found between perceived availability of social support and current attenuated psychotic symptoms for all support domains, except for perceived support from family members ($r_s = -.193$; $p = .09$). In the HC group, no correlations were found between perceived availability of social support and symptoms for all support domain. Further to this, in the UHR group negative correlations were found between perceived availability of emotional support and perceived availability of practical support and current attenuated psychotic symptoms ($r_s = -.318$; $p = .011$ and $r_s = -.347$; $p = .005$, respectively), and this was also the case in the HC group ($r_s = -.494$; $p < .001$ and $r_s = -.295$; $p = .027$, respectively). In the HC group, perceived availability of emotional support was also found to be negatively correlated with current depressive symptoms ($r_s = -.293$; $p = .030$). Finally, in the HC group positive correlations were found between participant's dissatisfaction with the amount of emotional support receive from others and current symptoms ($r_s = .358$; $p = .006$ for current attenuated psychotic symptoms; $r_s = .402$; $p = .002$ for current depressive symptoms).

Table 2 Correlations between social support measures (MSPSS and SOS) and total attenuated psychotic symptom scores on the PQ and total depressive symptom scores on the BDI for UHR participants.

Group	Social Support measure	Domain		Psychotic symptom score	Depressive symptom score
UHR	MSPSS: Perceived Availability	Significant Others	Correlation coefficient	-.299**	-.284*
			p-value	.008	.015
		Family	Correlation coefficient	-.193	-.235*
			p-value	.090	.045
		Friends	Correlation coefficient	-.447**	-.620**
			p-value	.000	.000
		Total	Correlation coefficient	-.389**	-.474**
			p-value	.000	.000
	SOS: Satisfaction with Social Support	Availability of emotional support	Correlation coefficient	-.318*	-.138
			p-value	.011	.282
		Satisfaction with emotional support	Correlation coefficient	.193	.165
			p-value	.127	.196
		Availability of practical support	Correlation coefficient	-.347**	-.154
			p-value	.005	.227
		Satisfaction with practical support	Correlation coefficient	.033	.128
			p-value	.798	.318

MSPSS, Multidimensional Scale of Perceived Social Support; SOS, Significant Other Scale; PQ, Prodromal Questionnaire; BDI, Beck Depression Inventory; UHR, ultra-high risk. Significant correlations ($p < 0.05$) are indicated by asterisks: *Correlation is significant at the 0.05 level; ** Correlation is significant at the 0.01 level.

Table 3 Correlations between social support measures (MSPSS and SOS) and total attenuated psychotic symptom scores on the PQ and total depressive symptom scores on the BDI for HC participants.

Group	Social Support measure	Domain		Psychotic symptom score	Depressive symptom score
HC	MSPSS: Availability of Social Support	Significant Others	Correlation coefficient	-.122	-.202
			p-value	.357	.139
		Family	Correlation coefficient	-.010	-.081
			p-value	.942	.556
		Friends	Correlation coefficient	-.105	-.038
			p-value	.428	.784
		Total	Correlation coefficient	-.096	-.138
			p-value	.471	.316
	SOS: Satisfaction with Social Support	Availability of emotional support	Correlation coefficient	-.494**	-.293*
			p-value	.000	.030
		Satisfaction with emotional support	Correlation coefficient	.358**	.402**
			p-value	.006	.002
		Availability of practical support	Correlation coefficient	-.295*	-.202
			p-value	.027	.143
		Satisfaction with practical support	Correlation coefficient	.146	.219
			p-value	.287	.114

MSPSS, Multidimensional Scale of Perceived Social Support; SOS, Significant Other Scale; PQ, Prodromal Questionnaire; BDI, Beck Depression Inventory; HC, healthy control. Significant correlations ($p < 0.05$) are indicated by asterisks: *Correlation is significant at the 0.05 level; ** Correlation is significant at the 0.01 level.

Stage 2 - Mediation Analysis

Figure 3 illustrates the indicators that were chosen for each latent variable within the mediation model. Correlations between indicators for each construct are presented in Table 4. The lack of correlations between indicators for perceived social support (i.e. between satisfaction and availability scores) suggests that these represent two different constructs. Therefore, two separate mediation models were run. Due to the lack of association between overall exposure to early adversity and attenuated psychotic symptoms found in previous analysis of this data by the OASIS research group (Day, 2012), simple mediation was run initially, excluding childhood adversity. The results of the CFA revealed poor model fit indices for both mediation models with perceived availability of or perceived satisfaction with social support as a mediator between recent stressful life events and current attenuated psychotic symptoms [$\chi^2 = 103$, $p < 0.001$, SRMR = 0.095, RSMEA = 0.16, CFI = 0.798; and $\chi^2 = 84$, $p = 0.00$, SRMR = 0.101, RSMEA = 0.176, CFI = 0.802 respectively].

A possible reason for the poor model fit could be the high correlation between indicators for stress (i.e. the total number of independent life stressful life events, the total number of dependent stressful life events, and the total number of 'very bad' stressful life event). Therefore, these three indicators were dropped and replaced with 'the total number of stressful life events that occurred in the past six months'. Figure 4 is a graphical illustration of the final two simple mediation models that were run. Fit indices for the two models were adequate for perceived availability of social support [$\chi^2 = 30$, $p = 0.03$, SRMR = 0.05, RSMEA = 0.09, CFI = 0.954] and good for perceived satisfaction with social support [$\chi^2 = 17.5$, $p = 0.09$, SRMR = 0.05, RSMEA = 0.08, CFI = 0.97].

Mediation 1: Recent stressful life events and perceived availability of social support

To assess pathways from recent stressful life events to current attenuated psychotic symptoms via levels of perceived availability of social support received from others, estimates of the total effects of the total number of stressful life events that occurred

in the past six months and of total perceived stress on symptoms were parsed into direct and indirect effects using mediation analysis, as detailed before. Results revealed that both the unadjusted direct and indirect effect of recent stressful life events on symptoms were not statistically significant at conventional 5% levels (see Table 5), indicating no evidence for full or partial mediation via perceived availability of social support.

Mediation 2: Recent stressful events and perceived satisfaction with social support

Mediation analysis was repeated to assess pathways from recent stressful life events to current attenuated psychotic symptoms via levels of perceived satisfaction with the social support received from others. As before, results revealed that both the unadjusted direct and indirect effect of recent stressful life events on symptoms were not statistically significant at conventional 5% levels (see Table 5), indicating no evidence for full or partial mediation via perceived satisfaction with social support.

Given the sample size of this study, one would expect to detect a medium mediation effect with 80% probability, if this was present (see Fritz & MacKinnon, 2007). This means that it would not be possible to detect a mediation effect with childhood adversity as an additional factor in the model(s), and it was therefore not necessary to repeat the mediation analysis.

Table 4 Correlations between indicators for latent variables in the mediation model.

Correlations between indicators for recent stressful life events			
		Perceived Stress Score	
Total number of life events in past 6 months	Pearson Correlation	.330**	
	p-value	.003	
Total independent life events in past 6 months	Pearson Correlation	.320**	
	p-value	.004	
Total dependent life events in past 6 months	Pearson Correlation	.182	
	p-value	.105	
Total 'very bad' life events in past 6 months	Pearson Correlation	.276*	
	p-value	.013	
Correlations between indicators for perceived social support			
		Satisfaction with emotional support	Satisfaction with practical support
Significant other total score	Pearson Correlation	-.172	-.045
	p-value	.165	.716
Family total score	Pearson Correlation	-.179	-.100
	p-value	.147	.420
Friends total score	Pearson Correlation	-.288*	-.164
	p-value	.018	.184
Correlations between indicators for attenuated psychotic symptoms			
		PQ negative subscale total	PQ disorganised subscale total
PQ negative subscale total	Pearson Correlation	1	.670**
	p-value		.000
PQ disorganised subscale total	Pearson Correlation	.670**	1
	p-value	.000	
PQ general subscale total	Pearson Correlation	.721**	.534**
	p-value	.000	.000

PQ, Prodromal Questionnaire. Significant correlations ($p < 0.05$) are indicated by asterisks: *Correlation is significant at the 0.05 level; ** Correlation is significant at the 0.01 level.

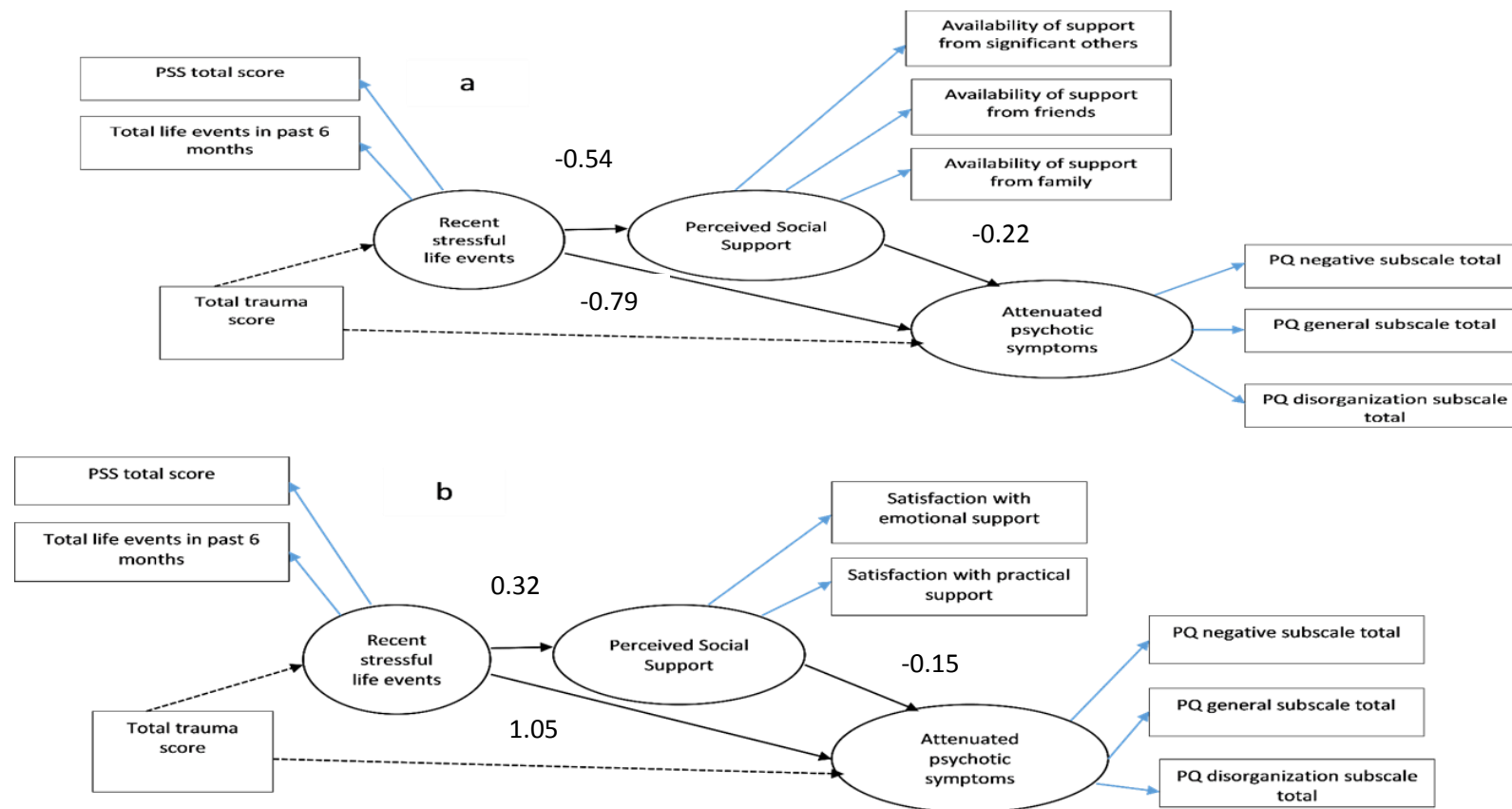


Figure 4 Mediation Model for (a) the effect of recent stressful life events on attenuated psychotic symptoms via availability of social support and (b) the effect of recent stressful life events on attenuated psychotic symptoms via satisfaction with social support.

Latent variables are represented by circles; indicators are represented by rectangles; blue arrows represent the measurement model: the relationships between the observed variables (indicators) and the latent variables; black arrows represent the structural model: the relationships between the latent variables; dotted arrows represent the untested relationship between the observed variable childhood adversity and the latent variables.

Table 5 Mediation Models: regression coefficients (B), 95% Confidence Intervals (CI) and p values for significant tests for direct, indirect and total effects for the mediation models for availability of and satisfaction with social support.

	<i>B</i> Coefficient	95% CI	<i>p</i>
Direct effects			
Mediation Model 1: stress -> availability of support -> symptoms	5.65	2.72-22.77	0.61
Mediation Model 2: stress -> satisfaction with support -> symptoms	6.79	3.90-20.21	0.24
Indirect effects			
Mediation Model 1: stress -> availability of support -> symptoms	0.84	-1.12-4.13	0.93
Mediation Model 2: stress -> satisfaction with support -> symptoms	-0.31	-3.84-0.07	0.89
Total effects			
Mediation Model 1: stress -> availability of support -> symptoms	6.49	-	-
Mediation Model 2: stress -> satisfaction with support -> symptoms	6.48	-	-

Discussion

The aims of this study were to investigate the role of perceived social support in the onset of psychosis, and to test the hypothesis that exposure to adverse and stressful life events increases the risk of psychotic symptoms and that this link is mediated by perceived social support.

Summary of main findings

In relation to the aims of this study and based on previous research in people with or at UHR of psychosis, the following three hypotheses were tested. The main findings will now be reviewed in terms of whether there was support for each of these hypotheses. Following the summary of findings, the results will be discussed in relation to previous research, clinical implications of the results will be considered, and recommendations for future work will be made.

Hypothesis:

1. Perceived Social Support

1.1 Perceived social support will be reduced in UHR participants compared to HC participants.

Hypothesis 1.1 supported:

UHR participants perceived their friends, family members and significant others to be less available to provide them with social support than HC participants. In addition, UHR participants reported receiving less emotional and less practical support from others than HC participants, and UHR participants were more dissatisfied with the amount of emotional support they received.

1.2 Perceived Social Support will be associated with current attenuated psychotic symptoms.

Hypothesis 1.2 supported:

Perceived availability of social support from friends and significant others was associated with current attenuated psychotic symptoms (and depressive symptoms) in UHR participants. Perceived availability of social support from family members was associated with current depressive symptoms, but not with attenuated psychotic symptoms in UHR participants. For HC participants, no associations were found between perceived availability of support from others and symptoms.

For both UHR and HC participants, associations between perceived availability of emotional and practical support and current attenuated psychotic symptoms were found.

No association between symptoms and reported levels of dissatisfaction with the amount of emotional or practical support received from others was found in UHR

participants. In HC participants, an association was only present between symptoms and dissatisfaction with the amount of emotional support received.

2. Associations between recent and lifetime adverse life events, perceived social support and attenuated psychotic symptoms

2.1 In the UHR group, the association between recent and lifetime adverse and stressful experiences and attenuated psychotic symptoms will be mediated by perceived social support.

Hypothesis 2.1 not supported:

No full or partial mediation via perceived availability of or perceived satisfaction with social support was found in pathways from recent and lifetime adverse and stressful life events to current attenuated psychotic symptoms.

Discussion of findings in relation to previous research

Few studies to date have examined perceived social support in a sample of individuals at UHR of psychosis (Willhite et al, 2008; Pruessner et al, 2011). The results from the present study are consistent with the model that people perceive their social support to be lower before the onset of psychosis, and findings from Pruessner and colleagues (2011) showing lower levels of perceived social support in the period before the onset of psychosis. Pruessner and colleagues (2011) used the MSPSS to measure perceived social support in first episode patients, UHR individuals and healthy controls and found that both first episode patients and UHR individuals reported less support than controls. The results of the present study extend these findings by further specifying and separating perceived availability of social support into emotional and practical support, and by additionally investigating perceived satisfaction with the amount of social support received. Interestingly, there was no difference between UHR participant's perception of their availability of emotional and practical support, with UHR participants reporting reduced availability of both forms of support compared to HC participants. In regards to satisfaction however, UHR participants reported being

significantly more dissatisfied with the amount of emotional support they received from others than HC participants. This is an interesting finding that has implications for clinical practice. It highlights the importance for a role of mental health, and in particular psychology, within early intervention services. Although contrary to expectations, no association was found between satisfaction with social support and symptoms in UHR individuals, it may be that the UHR sample of this study was too heterogeneous and/or small in number to detect this association. An association was found in HC participants, with those HC participants that reported less satisfaction with the amount of emotional support they received also reporting more symptoms.

The present study found that for both UHR and HC participants the perceived amount of emotional and practical support they received from others were associated with current attenuated psychotic symptoms, in that participants reporting less support also reporting more symptoms. These findings are consistent with previous literature that has consistently shown stronger links between health and perceived social support (Ibarra-Rovillard & Kuiper, 2011) than received social support.

Our findings also included associations between current attenuated psychotic symptoms and perceived availability of support from friends and significant others in UHR individuals. Interestingly, an association between perceived availability of social support from family members was only present with current depressive symptoms in UHR individuals, and no association between availability of social support (from friends, family members and significant others) and symptoms was found in HC participants. These findings are interesting considering that some studies have suggested that clinical cases have a greater proportion of family members in their social networks relative to friends (Tolsdorf, 1976; Grayer-Anderson & Morgan, 2012). It may then be that the narrowing of an individual's social contact with friends and significant others decreases opportunity for these individuals to form relationships, share problems and discuss feelings. This is consistent with the hypothesis that social support may have a protective effect on psychosis risk through exposing individuals to alternative explanations of unusual experiences, which may play a key role in the development and maintenance of psychotic appraisals of such phenomena (Garety, et

al, 2001; White et al, 2000). Furthermore, it may be that the importance of receiving this form of support from friends and significant others is independent of receiving support from family members. On the other hand, it may also be that receiving this form of social support from friends and significant others provides an important alternative to that received from family members. These findings bare further valuable considerations for clinical practice. The only previous study that investigated associations between perceived social support and symptom severity in an UHR group was conducted by Pruessner and colleagues (2011). They found a significant association between lower perceived support and higher negative symptoms (as well as a significant association between greater perceived support and better overall functioning). However, the authors used the MSPSS total score and thus do not provide information on associations separately for support domains (i.e. family, friends and significant others). There is, however, some evidence suggesting that availability of social support from non-family members has greater beneficial effects on negative symptoms and functioning in individuals with a first episode of psychosis (FE). For example, DeVlyder and Gearing (2013) reported that reduced peer support prior to first hospitalization for a psychotic episode was associated with an increase in symptom severity. Similarly, Suedermann and colleagues (2013) measured the presence or absence of a confidant in a group of individuals with a FE and found that the absence of a confidant was more strongly associated with negative symptom severity. Tentatively, the results from this study are consistent with the research in FE individuals, which suggests the importance of available social support from friends and significant others at the onset of psychosis, which may be qualitatively different from that received from family.

Contrary to expectations, the present study did not find evidence that perceived availability or perceived satisfaction with social support mediates (fully or partially) the relationship between recent and lifetime adverse and stressful life events and current attenuated psychotic symptoms. This is consistent with a previous study in which protective factors did not moderate the relationship between stress and psychosis symptoms, although SEM was not used in this study (Pruessner et al, 2011). This could mean that stress and childhood adversity need to be addressed more directly in clinical

practice. On the other hand, previous studies have suggested that it may be chronic exposure to everyday stress or hassle that might be more relevant to psychotic symptoms than major stressful life events (Norman & Malla, 1992; 1993a). As such, the indicators used within the latent variable analysis in the SEM of this study may not sufficiently define stressful life events. Assessing the total number of stressful events an individual has experienced has been criticized in previous research (Nuechterlein et al, 1989; Pallanti et al, 1997). Future studies investigating mediation between stress, social support and psychotic symptoms with SEM should consider using alternative stress indicators.

Clinical Implications

The detection of people at UHR for psychosis and the provision of clinical services for these individuals has facilitated considerable research in recent years into the factors associated with the onset of psychosis and the effectiveness of novel interventions in UHR groups (McGorry, et al., 2008; Ruhrmann, et al., 2009). At present, early intervention teams are unable to identify those UHR individuals who are going to develop psychosis on purely clinical grounds. The identification of markers for psychosis risk and response to intervention are thus key objectives in early psychosis research. These would allow early intervention services to identify those individuals who are most at risk of developing psychosis at an earlier stage and target interventions appropriately and effectively.

The results of the present study have several implications for clinical practice. First, perceived social support was significantly lower in UHR individuals than HC individuals for all support domains (family, friends and significant others) and for all functional aspects of support (practical and emotional), indicating that reduced social support may be an important risk factor for the development of the UHR state and psychosis. This is significant because social support has also been associated with poorer physical health and poorer treatment outcomes in people with psychosis (Greenblatt & Becerra et al, 1982; Morgan et al, 2008). Thus it is important that these factors are identified in people at UHR for psychosis and that appropriate support is provided.

In addition to overall lower perceived social support, UHR participants were less satisfied with the amount of emotional support they received. Satisfaction with the amount of emotional support provided was associated with current attenuated psychotic symptoms and depressive symptoms in HC individuals. Although this association was not found in the UHR group, this may have been due to sample size and heterogeneity. Nevertheless, this indicates importance and opportunity to provide intervention directed towards improving the ability to cope with emotional experiences, which may then lead to a reduction in the severity of symptoms, or at least in distress related to the experience of symptoms. In addition, targeted interventions could be beneficial in helping the individual to develop an understanding of his or her mental health difficulties which lends itself well to psychological therapy approaches such as Cognitive Behavioural Therapy (CBT; Morrison, 2009). In any case, these results highlight the importance for mental health input into early intervention teams and are consistent with the clinical stage model of psychosis (McGorry et al, 2009) which proposes the use of safer and more psychological interventions for UHR individuals (Bechdolf et al, 2006).

The findings that perceived support from friends and significant others were associated with current attenuated psychotic symptoms and depressive symptoms, whereas perceived support from family members was associated with depressive symptoms only in UHR individuals suggest that support from friends and significant others may be particularly important in this group and a contributing factor to the development of psychosis risk. This highlights the importance of targeted interventions directed towards improving individual's social skills and (re-) integration into work, school and community living. This is also important in relation to recent evidence which suggests that many individuals at UHR who do not convert to full-blown psychosis in the long term remain at lower level of functioning than matched HC (Addington et al, 2011; Brandizzi et al, 2015). Moreover, these results suggest the potential value of delivering interventions in group settings with this population.

Finally, the results of the present study do not provide support for a mediating effect of perceived social support between recent and lifetime adverse and stressful life

events and current attenuated psychotic symptoms. However, there were methodological limitations to the definition of recent stressful life events in the mediation analysis of the study. Further research employing improved or alternative stress measures in the UHR group may yet reveal a mediation effect which could be of use clinically. On the other hand, the lack of mediation could mean that childhood adversity and recent stressful experiences need to be addressed more directly in early intervention settings. For example, this could include targeted interventions directed towards stress reduction training and/or individualized approaches that identify stress trigger situations and modify the appraisal of stress. Similarly, it would undoubtedly be beneficial to direct support and interventions to people who have been exposed to childhood adversity. Although the feasibility of doing this is questionable given the difficulties in identifying people who have experienced the forms of adversity implicated in psychosis and the low rates of disclosure of abuse (Gilbert et al, 2009a), there is some evidence that interventions in such groups is associated with positive outcomes (MacMillan, et al, 2009; Ramachandani & Jones, 2003).

Recommendations for future research

A growing body of research has started investigating possible relationships between known social psychosis risk factors through mediation or moderation analyses. Although, to the best of the author's knowledge, no studies to date have examined multiple mediation analysis including combinations between social support and recent and lifetime adverse and stressful life events in relation to psychosis. There are a number of ways how social factors may relate to each other in pathways to psychosis, and social support, childhood adversity and recent stressful life events may only represent some of the pieces in a complex illness matrix.

Coping could be a possible further related factor. Coping is an important element in the transactional model of stress and there is considerable inter-individual variation in the ways that individuals cope with stressful life events (Lazarus & Folkman, 1984). Certain types of coping responses are thought to cluster together to form coping styles that an individual will use when facing stressful life events, and the type of coping used in response to mental health problems has been linked to outcome (McGlashan, 1987).

Individuals experiencing various mental health problems, such as psychosis or depression, have been found to be more likely to use avoidant coping styles (Tait et al, 2004), and such avoidant coping styles appear to be associated with poorer outcome (McGlashan, 1987; Thompson et al, 2003). On the other hand, coping which involves active processes such as problem solving is considered to be more adaptive and has been linked to better outcome in people with psychosis (Thompson et al, 2003). Accordingly, the way in which an individual copes with a stressful life event could affect both the perceived severity of that event and its impact on her or his mental state. In addition, social support is considered to be a vital resource for coping processes (Taylor & Stanton, 2007).

Evidence for a close relationship between these three factors and their influence on physical and mental health outcome is further suggested by research in the field of addictions. The stress-strain-coping-support (SSCS) model (Orford et al, 1998; 2010 see Figure 5 below) proposes a way in which stress, coping, social support and strain (i.e. physical and/or psychological ill health) interconnect, and this model underpins a widely used and efficacious intervention (i.e. the 5-Step Method) for family members of individuals with an alcohol or substance misuse problem. The SSCS model assumes that having a close relative with an alcohol or substance misuse problem constitutes a form of stressful life circumstances which puts affected family members (AFM) at risk of experiencing strain. Good quality social support, in the form of emotional support, good information, and material help, is an invaluable resource for AFM, supporting their coping efforts and contributing positively to their health.

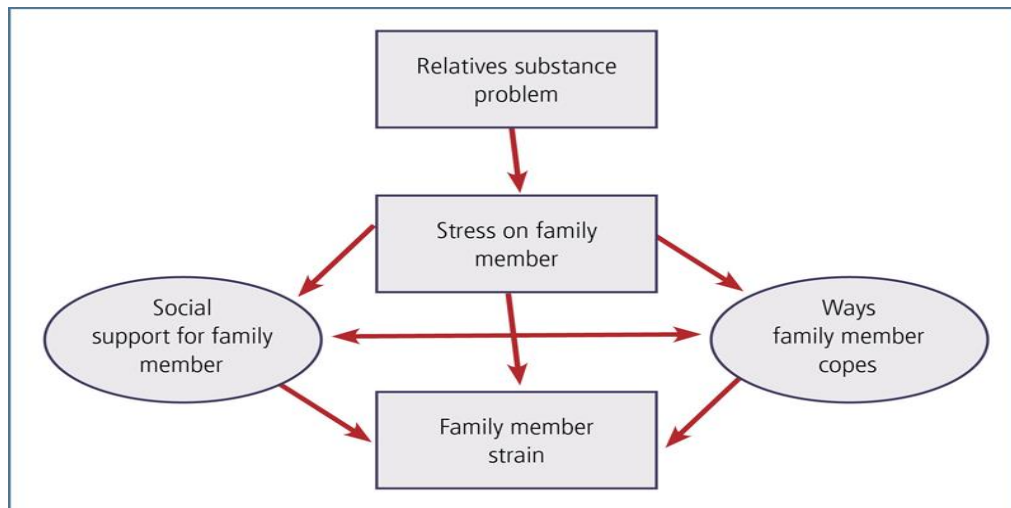


Figure 5 The Stress-Strain-Coping-Support (SSCS) model (Orford et al, 1998)

Although the SSCS model was developed in the context of addictions and is primarily concerned with the well-being of AFM, its theoretical basis also appears applicable to psychosis, and specifically factors involved in the development of psychosis. As such, individuals at UHR of psychosis may experience stressful life events that influence subsequent symptom severity in these individuals. This association may be further influenced by the individual's perceived social support and their coping resources (see Figure 6 below for an adapted SSCS model).

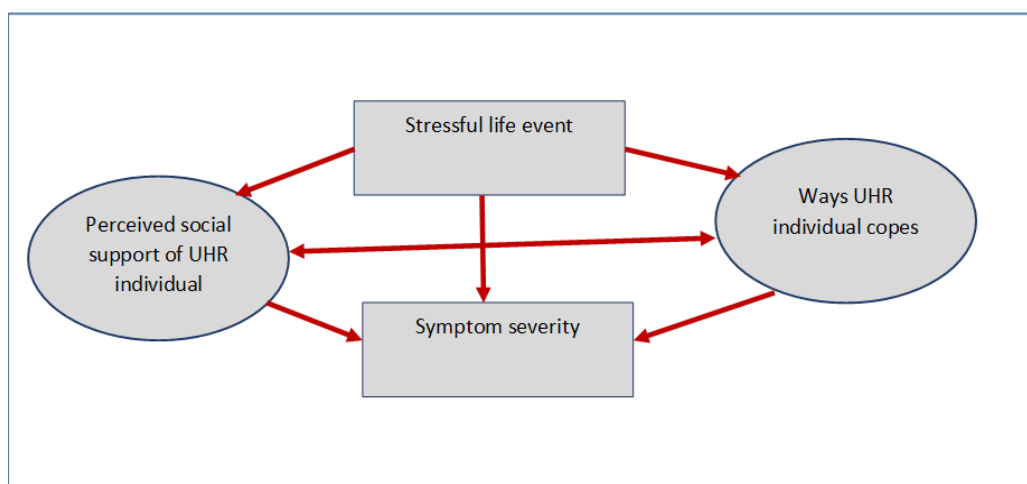


Figure 6 Adaptation of the SSCS to psychosis risk factors

Very few studies to date have investigated stress, social support and coping in individuals at UHR of psychosis, and only one study has explored the possible interplay

between these factors. Phillips and colleagues (2012) compared the experiences of stress and coping between individuals at UHR of psychosis and HC. The authors found that the UHR group reported feeling significantly more distressed by recent life events and felt coping poorer than the HC group. Moreover, the UHR group was more likely to utilize emotion-oriented coping strategies than the HC group, and less likely to utilize active coping strategies. Although perceived social support (or the absence of this) was mentioned in this study as a possible contributor to the reduced sense of control over experience in the UHR group, perceived social support was not formally assessed. In a further study, Pruessner and colleagues (2011) compared self-report measures of stress, social support and coping in individuals with a FE of psychosis, individuals at UHR of psychosis and HC participants. They found that UHR individuals reported both lower social support and active coping than HC, although neither of these factors were found to moderate the relationship between stress and symptom severity.

Another possible factor in the complex psychosis matrix could be perceived social support in childhood. Unfortunately, data on perceived social support in childhood was not collected for this study and investigation of this was therefore not possible. However, some recent preliminary studies have started to investigate perceived social support in childhood as a potential moderator or mediator in the relationship between childhood adversity and psychosis risk, as well as in the relationship between stress and psychosis risk. For example, Gayer-Anderson and colleagues (2014) explored whether perceived childhood social support modified the association between childhood trauma and psychosis, in a retrospective study of individuals with a first episode of psychosis. They found that the effects of severe physical abuse in childhood on psychosis was mainly mediated through low perceived childhood support. Similarly, Gardener and colleagues (2012) assessed the relationship between recent stressful life events, childhood support and risk for psychosis. The authors found a possible effect of childhood social support in moderating the relationship between stressful life events and risk of psychosis, in first episode patients. However, in both of these studies participant numbers were relatively small and these studies reported on FE patients. Replication with larger samples and in UHR populations is warranted. Nevertheless, these preliminary studies suggest that perceived social support in childhood may form

an important additional protective factor against psychosis. Investigating its relationship to perceived social support in adulthood, as well as its interplay with risk factors (i.e. childhood adversity and stressful life events) and other resilience factors (i.e. social support in adult hood and coping) will be an interesting next step in exploring possible pathways to psychosis.

Finally, recent research has also increasingly begun to investigate evidence for pathways between specific types of adversities (in both childhood and adulthood) and specific symptoms of psychosis (e.g. Sitko et al, 2014; Bentall et al, 2014, 2012; Varese et al, 2011; Reiff et al, 2011; Toth et al, 2011). Although one of the strengths of the presented study lies in the large number of employed measures, which would enable the investigation of specific adversities and forms of social support, data on specific symptoms was not collected. Future studies investigating evidence for pathways between specific types of adverse experiences (in both childhood and adulthood), specific types of social support (in both childhood and adulthood) and specific symptoms of psychosis will have further potential to explain the mechanism that lead to psychosis and may considerable clinical implications.

Methodological Limitations

The present study has several methodological strengths. It is the largest UHR sample in which multiple measures of perceived social support were assessed, and the inclusion of a group of HC participants similar in distribution of the matching variables age, gender, ethnicity, migration status, and geographical area is an improvement on previous studies where such a comparison group was not included. Nevertheless, there are also several potential limitations to the present study which need to be kept in mind when considering the findings.

One limitation of the study in achieving its aim of investigating the relationships between social support, recent and lifetime adverse and stressful life events and psychosis is the fact that the study was cross-sectional in design. A potential advantage of performing research with UHR groups is that participants can be studied prospectively, and measures of interest obtained at the baseline assessment can then

be related to the later onset of psychosis in the same individuals. However, in the absence of clinical follow up of the present UHR sample, it was not possible to draw any conclusions regarding causality for the measures found to be associated with the UHR status and attenuated psychotic symptoms. The follow up of participants is currently ongoing and once this process is complete, it will be possible to investigate the relationship between social support, recent and lifetime adverse and stressful life events and the onset of psychosis further.

Another limitation of the study was that the UHR and HC groups were not matched for certain socio-demographic characteristics. While the UHR and HC groups were similar in distribution of matching key demographic variables of age, gender, ethnicity, migration status, and country of birth, there were significant differences in social class (based on parental occupation), employment status, and level of education. It is possible that these factors might be related to social support (or childhood adversity or stressful life event) measures investigated in this study and thus account for some of the observed group differences. Broadly defined, social disadvantage (including e.g. lower social class) has been found to persist over time (Pantazis et al, 2006) and it is often associated with poor outcome in a number of domains (including e.g. education and employment status). These outcomes may in turn further intensify disadvantage and create for many individuals a downward cycle of poverty and perceived or actual exclusion. As such, the shorter time spent in education and the longer time spent unemployed in the UHR group might have decreased their opportunity for forming relationships and thus significantly impacted on their perception of available social support. Similarly, lower social class and level of education might have led to increased risk of childhood adversity in the first place, as well as possible further exposure to adverse and stressful life events later in life. However, unemployment and dropping out of education are also both possible consequences of the development of the UHR state and therefore it becomes problematic to try to match UHR and HC participants on these variables, as this might reduce the size of any genuine differences between the groups because of an over-representation of HC participants exposed to the potentially negative consequences of unemployment and low educational achievement. Recruitment of more HC participants from similar backgrounds to the

UHR participants, however, would improve the comparability of the two groups by allowing the assumption that UHR and HC participants would be equally likely to have been exposed to any adverse experiences potentially associated with coming from different social class backgrounds and effort should be made in future studies to ensure better matching of participants in this regard. In addition, although the UHR and HC groups were similar in distribution of the matching demographic variable age (with an average age of 23 years in both groups), the large range in ages (i.e. between 14-35 years) of UHR participants might have led to significant heterogeneity within this group, which in turn might have impact on the genuineness of the relationship between perceived social support and psychotic symptoms in this group (although it is to note that the inclusion criteria age of UHR individuals was predetermined by the referral criteria of the early intervention service from which this sample was required). Social support, as well as perceptions of its importance and adequacy, undoubtable change with age and the need for parental involvement is usually greater in early years. Similarly, high rates of psychotic experiences are reported in young people, with higher prevalence rates adolescents than in adulthood (see e.g. Kelleher et al, 2012).

Another potential limitation of the present study relates to the type of sampling used to recruit participants. Both UHR and HC participants were convenience samples, and the 'snowball sampling' method was employed in an attempt to ensure that HC participants were well-matched on socio-demographic factors to the UHR group. It would have been preferable to perform the research assessment in a consecutively ascertained group of clients at OASIS in order to avoid any selection bias that might take place. As a result of the convenience sample used in this study, the generalisability of the findings to the whole UHR group is limited; however, the socio-demographic and clinical characteristics of the sample are similar to that of the OASIS client group as a whole, which suggests that the sample might be reasonably representative of the help-seeking UHR group overall. Another factor affecting the generalisability of the findings is that clients of services such as OASIS for young people at high risk of developing psychosis may not be representative of all people in the general population who are at risk. This issue is common to all research in UHR groups as, in order to justify early intervention services such as OASIS from an ethical position,

the individuals are necessarily help-seeking. It is possible that the characteristic of being help-seeking is in some way associated with the measures assessed in this study, and so the reliance on a sample of help-seeking UHR participants in attempting to investigate the relationship between social support and psychosis could mask any genuine associations that might exist.

A further limitation of this study is that the possible confounding effect of comorbid mental health problems of UHR participants was not investigated. Experiences of trauma and other stressful experiences have been found to be more common in a range of mental health problems, including depression (Bifulco, et al., 1991), and PTSD (Morrison, et al., 2003). High rates of comorbid symptoms and diagnoses are often found in people with psychosis (Bendall, et al., 2008a) and this is also true in people at high risk of developing psychosis (Haroun, et al., 2006; Yung, et al., 2004). This calls into question the specificity of any associations between stressful and traumatic experiences and psychosis. As no record of comorbid symptoms was available for the present sample, with the exception of current symptoms of depression, it was not possible to address this issue fully, although comprehensive assessment of symptom profile, as well as the development of any supra-threshold mental health problems aside from psychosis, at follow up will allow investigation of the specificity of the association between stressful and traumatic experiences and psychosis.

In order to try to overcome the limitation of many studies investigating stress and psychosis, the present study involved a comprehensive assessment of experiences of stressful life events in the present or recent past. However, the types of stress investigated in this study are not exhaustive and many experiences that could also have been relevant might not have been recorded. These include, for example, serious accidents, illnesses, or natural disasters, as well as prenatal stress and obstetric complications. Efforts should be made in future studies to use alternative, more comprehensive stress measures. This may also influence potential future SEM analysis for which the use of representative stress indicators is curial. Similarly, the number of items to measure latent constructs was relatively small. Future studies should

therefore employ a larger number of items, as this would allow better measurement of latent constructs.

Conclusion

In summary, the findings of the present study indicate that social support, or at least the perceived availability of and satisfaction with it, is not only reduced in individuals at UHR of psychosis, but related to attenuated psychotic symptoms. Whether or not this is the result of a lack of social contact or supportive relationships overall or following social withdrawal associated with symptom onset is not possible to determine at present. Further analysis of follow-up data with regard to clinical outcome will shed further light on the relationship between social support and its role in the onset of psychosis. Nevertheless, results suggests a crucial role of emotional support, as well as support provided by friends and significant others in UHR individuals. Specific interventions targeting these factors (such as CBT, social skills training, and group based settings) might be beneficial for the UHR population, and the routine use of such interventions should be promoted. This would also be consistent with the stage model of psychosis (McGorry et al, 2009) which proposes the use of safer and more psychological interventions for UHR individuals (Bechdolf et al, 2006). In addition to improving individual's wellbeing, these psychological interventions have the potential to prevent a transition to psychosis (Bechdolf et al., 2006; Morrison et al., 2007; Morrison et al., 2004; Nordentoft et al., 2006). The findings of this study do not suggest that perceived social support mediates the relationship between recent and lifetime adverse and stressful life events and psychosis. Future studies using an even larger sample of UHR individuals and alternative stress measures are needed to model potential pathways.

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Appendices

Appendix 1: Personal Assessment and Crisis Evaluation (PACE) criteria for identification of the ultra-high risk (UHR) of psychosis status

The PACE criteria identify young people (14-35 years old) at UHR of developing psychosis. Previous studies have shown that around 35 per cent of these individuals go on to develop psychosis within 12 months (Cannon, et al., 2007; Yung, et al., 2004). An individual can meet the PACE criteria for being at UHR in one or more of three ways:

Attenuated positive psychotic symptoms – experience of symptoms qualitatively similar to those of psychosis but of insufficient severity and frequency to meet criteria for a diagnosis of psychosis;

A brief episode of frank psychosis of less than one week's duration that resolved without antipsychotic medication (Brief Limited Intermittent Psychosis or BLIP); and

A recent decline in function (defined as a 30% reduction in scores on the Global Assessment of Function scale; GAF) over the past year, coupled with either schizotypal personality disorder or a first-degree relative with a psychotic disorder.

Appendix 2: Participant Information and Consent Form

DATE

8th August 2006

Participant Information and Consent Form

SALIVARY CORTISOL AND STRESS IN PEOPLE WITH PRODROMAL SYMPTOMS

You are being invited to take part in a study being conducted in the South London & Maudsley NHS Trust by Professor McGuire.

Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends, relatives and your GP if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Consumers for Ethics in Research (CERES) publish a leaflet entitled 'Medical Research and You'. This leaflet gives more information about medical research and looks at some questions you may want to ask. A copy may be obtained from CERES, PO Box 1365, London, N16 0BW

Thank you for reading this.

WHAT IS THE PURPOSE OF THE STUDY?

People who are experiencing symptoms that suggest they could be at risk of developing a mental illness (prodromal symptoms) may also be experiencing stress and changes in hormone levels in their blood (cortisol). This study will measure cortisol in your saliva and assess exposure to stressful and traumatic experiences throughout your life, along with several aspects of your psychological state at or around the time of the salivary measurements. Salivary samples are obtained by chewing on a pad and inserting it into a sealed container. The samples may be mailed back to the researchers, or other means of recovery may be arranged.

WHY HAVE I BEEN CHOSEN?

You have been invited to take part because you are experiencing symptoms that suggest you may be at risk of developing a mental health problem – all people who attend the OASIS service are invited to participate.

WHAT WILL HAPPEN TO ME IF I TAKE PART?

Everyone who decides to take part in the study will be interviewed by one of the researchers for about thirty minutes every 6 months. During the interviews, the researcher will ask you about how you have been feeling and recent experiences you have had. At the first meeting you will be asked to complete some questionnaires as well, which should take about 90 minutes. You will be then given the collection containers for the saliva samples and asked to return them after use. The samples will be taken at 7 times during a 24 hour period: directly after waking, 15, 30, 60 and 90 minutes after waking. Then a further two samples at 12 noon and 8 p.m.

WHAT ARE THE POSSIBLE DISADVANTAGES AND RISKS OF TAKING PART?

Since you are taking no medications there is very little potential risk in taking part in this study. Care should be taken not to swallow the pads that will be chewed to gather the saliva.

WHAT IF SOMETHING GOES WRONG?

The researchers will not compensate you where such injury results from any procedure carried out which is not in accordance with the protocol for the study. Your right at law to claim compensation for injury where you can prove negligence is not affected.

WILL MY TAKING PART IN THIS STUDY BE KEPT CONFIDENTIAL?

If you consent to take part in the research any of your medical records may be looked at by people from the research group to check that the study is being carried out correctly. Your name, however, will not be disclosed outside the hospital/GP surgery. By signing the consent form you are giving permission for this to be done.

Your GP will be notified about your participation in this study, but only after we have agreement from you to contact them.

The information collected during the study will be stored in a computer but your name will not be linked to it in any way.

If during the course of this study we obtain information that may be clinically important for your health, we will inform you of this and, with your permission, contact your GP or other appropriate health professionals.

WHAT WILL HAPPEN TO THE RESULTS OF THE RESEARCH STUDY?

The results of the study are unlikely to be published before 2009/2010. Copies of the published results will be available to you on request. The researcher will also explain the results to you in person.

WHO IS ORGANISING AND FUNDING THE RESEARCH?

This study is being carried out as part of the research associated with the Lambeth Early Onset Services.

WHO HAS REVIEWED THE STUDY?

An ethics committee has reviewed the study for compliance with medical and ethical standards and for scientific value.

CONTACT FOR FURTHER INFORMATION

Whenever you want to get more information on this study, please contact:

Miss Fern Day

Address: PO67
Institute of Psychiatry
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E-mail: fern.day@iop.kcl.ac.uk

Thank you for considering taking part in this study. You will be given a copy of the information sheet and a signed consent form to keep.

Participant Number:

Participant Initials:

CONSENT FORM

Title: Salivary Cortisol and Stress in People with Prodromal Symptoms

Name of Investigator:

Please
initial box

I confirm that I have read and understand the information sheet dated 8th August 2006 for the above study and have had the opportunity to ask questions.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

I understand that the information that I provide will be processed and analysed as is required by this research study and according to the Data Protection Act.

I consent to my General Practitioner/Consultant being informed that I am in this study.

I agree to take part in the above study.

I consent to having the results of this study correlated with the results of any other research studies I might participate in.

Name of Participant

Date

Signature

Name of Person taking consent
(if different from researcher)

Date

Signature

Researcher

Date

Signature

Appendix 3: Assessment measures and their coding procedure

3.1 The Prodromal Questionnaire (PQ)

PQ

Prodromal Questionnaire

By Rachel Loewy, Adrian Raine and Tyrone Cannon.

©University of California, Los Angeles

ID: _____

Age: _____

Date: _____

May 2002

This questionnaire asks a number of questions about your thoughts, feelings, and experiences. Please read each item carefully and indicate whether you agree or disagree with it by circling true or false in the right-hand margin next to that item. Please try to answer each question.

- | | | | |
|-----|---|------|-------|
| 1. | I am easily distracted by noises or other people talking. | True | False |
| 2. | The passage of time feels unnaturally faster or slower than usual. | True | False |
| 3. | I often have difficulty organizing my thoughts or finding the right words. | True | False |
| 4. | When I look at a person, or look at myself in a mirror, I have seen the face change right before my eyes. | True | False |
| 5. | I sometimes get strange feelings on or just beneath my skin, like bugs crawling. | True | False |
| 6. | I do not get along well with people at school or at work. | True | False |
| 7. | Familiar surroundings sometimes seem strange, confusing, threatening or unreal. | True | False |
| 8. | I often seem to live through events exactly as they happened before (déjà vu). | True | False |
| 9. | I sometimes smell or taste things that other people can't smell or taste. | True | False |
| 10. | I have difficulty concentrating, listening or reading. | True | False |
| 11. | I have had troubles at school or work recently. | True | False |
| 12. | Sometimes I think that people can read my mind. | True | False |
| 13. | I have heard things other people can't hear like voices of people whispering or talking. | True | False |
| 14. | I can't express my feelings as well as I used to. | True | False |
| 15. | I have interests that other people find odd. | True | False |
| 16. | I have lost a sense of who I am. | True | False |
| 17. | I am less interested than I used to be in keeping clean or dressing well. | True | False |
| 18. | I often hear unusual sounds like banging, clicking, hissing, clapping or ringing in my ears. | True | False |

19.	I often mistake shadows for people or noises for voices.	True	False
20.	Things that I see appear different from the way they usually do (brighter, duller, larger, smaller, or changed in some other way).	True	False
21.	I tend to be very quiet and keep in the background on social occasions.	True	False
22.	People sometimes stare at me because of my odd appearance.	True	False
23.	I wander off the topic or ramble on too much when I am speaking.	True	False
24.	I believe in telepathy, psychic forces, or fortune-telling.	True	False
25.	I often feel that others have it in forme.	True	False
26.	My sense of smell sometimes becomes unusually strong.	True	False
27.	Sometimes I have felt that I'm not in control of my own ideas or thoughts.	True	False
28.	I have been feeling unhappy or depressed lately.	True	False
29.	Everyday things affect me more than they used to.	True	False
30.	I believe that I am especially important or have abilities that are out of the ordinary.	True	False
31.	Other people think that I am a littlestrange.	True	False
32.	Sometimes my thoughts seem to be broadcast out loud so that other people know what I am thinking.	True	False
33.	I often feel that I have nothing to say or very little to say.	True	False
34.	I am unusually sensitive to noise.	True	False
35.	I am superstitious.	True	False
36.	I have heard my own thoughts as if they were outside of my head.	True	False
37.	I have trouble focusing on one thought at a time.	True	False
38.	I often feel that other people are watching me or talking about me.	True	False
39.	I get very nervous when I have to make polite conversation.	True	False
40.	People comment on my unusual mannerisms and habits.	True	False
41.	I am less interested in school or work lately.	True	False

42.	I find it hard to be emotionally close to other people.	True	False
43.	I tend to avoid social activities with other people.	True	False
44.	I feel very guilty.	True	False
45.	I am an odd, unusual person.	True	False
46.	I sometimes feel that things I see on television or read in the newspaper have a special meaning for me.	True	False
47.	My moods are highly changeable and unstable.	True	False
48.	I have been unable to enjoy things that I used to enjoy .	True	False
49.	My thinking feels confused, muddled, or disturbed in some way.	True	False
50.	Sometimes I feel suddenly distracted by distant sounds that I am not normally aware of.	True	False
51.	Recently, I have begun talking to myself.	True	False
52.	I have had the sense that some person or force is around me, even though I could not see anyone.	True	False
53.	I am in danger of failing out of school, or have been fired from my job.	True	False
54.	I have some eccentric (odd) habits.	True	False
55.	At times I worry that something may be wrong with my mind.	True	False
56.	I have felt that I don't exist, the world does not exist, or that I am dead.	True	False
57.	I have been confused at times whether something I experienced was real or imaginary.	True	False
58.	People find me aloof and distant.	True	False
59.	I tend to keep my feelings to myself.	True	False
60.	I have experienced unusual bodily sensations (tingling, pulling, pressure, aches, burning, cold, numbness, shooting pains, vibrations or electricity).	True	False
61.	I hold beliefs that other people would find unusual or bizarre.	True	False
62.	People say that my ideas are strange or illogical.	True	False
63.	I feel worthless.	True	False

64.	I feel that parts of my body have changed in some way, or that parts of my body are working differently than before.	True	False
65.	My thoughts are sometimes so strong that I can almost hear them.	True	False
66.	I am not very good at returning social courtesies and gestures.	True	False
67.	I sometimes see special meanings in advertisements, shop windows, or in the way things are arranged around me.	True	False
68.	I often pick up hidden threats or put-downs directed at me in what people say or do.	True	False
69.	I sometimes use words in unusual ways.	True	False
70.	I am often angry, easily irritated or offended.	True	False
71.	I have felt like I am looking at myself as in a movie, or that I am a spectator in my own life.	True	False
72.	I am less able to do usual activities or tasks.	True	False
73.	I have not been sleeping well lately.	True	False
74.	At times I have felt that some person or force interferes with my thinking or puts thoughts into my head.	True	False
75.	I have had experiences with the supernatural, astrology, seeing the future or UFOs.	True	False
76.	Some people drop hints about me or say things with a double meaning.	True	False
77.	I am often concerned that my closest friends, classmates, or co-workers are not really loyal or trustworthy.	True	False
78.	I have little interest in getting to know other people.	True	False
79.	I have seen unusual things like flashes, flames, blinding light, or geometric figures.	True	False
80.	I get extremely anxious when meeting people for the first time.	True	False
81.	I have felt like I am at a distance from myself, as if I am outside my own body or that a part of my body did not belong to me.	True	False
82.	I find that when something sad happens, I am no longer able to feel sadness, or when something joyful happens, I can no longer feel happy.	True	False

83.	I cry often.	True	False
84.	I have seen things that other people apparently can't see.	True	False
85.	I feel unable to carry out everyday tasks because of fatigue or lack of motivation.	True	False
86.	Everyday things are more stressful than before, like school or work, social situations, deadlines or changes in a schedule.	True	False
87.	I often avoid going to places where there will be many people because I will get anxious.	True	False
88.	I have felt more nervous or anxious lately, and find it hard to relax.	True	False
89.	I feel uninterested in the things I used to enjoy.	True	False
90.	People often find it hard to understand what I am saying.	True	False
91.	I have trouble remembering things.	True	False
92.	People say that I seem "spacey" or "out of it".	True	False

3.2 The Beck Depression Inventory – 2nd edition (BDI-II)

Participant Number _ _ _ _

Date _ _ / _ _ / _ _ _ _

BECK INVENTORY

- | | | |
|-----|---|---|
| 1. | 0 | I do not feel sad. |
| | 1 | I feel sad. |
| | 2 | I am sad all the time and can't snap out of it. |
| | 3 | I am so sad or unhappy that I can't stand it. |
| 2. | 0 | I am not particularly discouraged about the future. |
| | 1 | I feel discouraged about the future. |
| | 2 | I feel I have nothing to look forward to. |
| | 3 | I feel that the future is hopeless and that things cannot improve. |
| 3. | 0 | I do not feel like a failure. |
| | 1 | I feel I have failed more than the average person. |
| | 2 | As I look back on my life, all I can see is a lot of failures. |
| | 3 | I feel I am a complete failure as a person. |
| 4. | 0 | I get as much satisfaction out of things as I used to. |
| | 1 | I don't enjoy things the way I used to. |
| | 2 | I don't get real satisfaction out of anything anymore. |
| | 3 | I am dissatisfied or bored with everything. |
| 5. | 0 | I don't feel particularly guilty. |
| | 1 | I feel guilty a good part of the time. |
| | 2 | I feel quite guilty most of the time. |
| | 3 | I feel guilty all of the time. |
| 6. | 0 | I don't feel I am being punished. |
| | 1 | I feel I may be punished. |
| | 2 | I expect to be punished. |
| | 3 | I feel I am being punished. |
| 7. | 0 | I don't feel disappointed in myself. |
| | 1 | I am disappointed in myself. |
| | 2 | I am disgusted with myself. |
| | 3 | I hate myself. |
| 8. | 0 | I don't feel I am worse than anybody else. |
| | 1 | I am critical of myself for my weaknesses or mistakes. |
| | 2 | I blame myself all the time for my faults. |
| | 3 | I blame myself for everything bad that happens. |
| 9. | 0 | I don't have any thoughts of killing myself. |
| | 1 | I have thoughts of killing myself, but I would not carry them out. |
| | 2 | I would like to kill myself. |
| | 3 | I would kill myself if I had the chance. |
| 10. | 0 | I don't cry any more than usual. |
| | 1 | I cry more now than I used to. |
| | 2 | I cry all the time now. |
| | 3 | I used to be able to cry, but now I can't even cry even though I want to. |
| 11. | 0 | I am no more irritated by things than I ever am. |
| | 1 | I am slightly more irritated now than usual. |
| | 2 | I am quite annoyed or irritated a good deal of the time. |

- 3 I feel irritated all the time now.
12. 0 I have not lost interest in other people.
1 I am less interested in other people than I used to be.
2 I have lost most of my interest in other people.
3 I have lost all of my interest in other people.
13. 0 I make decisions about as well as I ever could.
1 I put off making decisions more than I used to.
2 I have greater difficulty in making decisions than before.
3 I can't make decisions at all anymore.
14. 0 I don't feel that I look any worse than I used to.
1 I am worried that I am looking old or unattractive.
2 I feel that there are permanent changes in my appearance that make me look unattractive.
3 I believe that I look ugly.
15. 0 I can work about as well as before.
1 It takes an extra effort to get started at doing something.
2 I have to push myself very hard to do anything.
3 I can't do any work at all.
16. 0 I can sleep as well as usual.
1 I don't sleep as well as I used to.
2 I wake up 1-2 hours earlier than usual and find it hard to get back to sleep.
3 I wake up several hours earlier than I used to and cannot get back to sleep.
17. 0 I don't get tired more than usual.
1 I get tired more easily than I used to.
2 I get tired from doing almost anything.
3 I am too tired to do anything.
18. 0 My appetite is no worse than usual.
1 My appetite is not as good as it used to be.
2 My appetite is much worse now.
3 I have no appetite at all anymore.
19. 0 I haven't lost much weight, if any, lately.
1 I have lost more than five pounds.
2 I have lost more than ten pounds.
3 I have lost more than fifteen pounds.
20. 0 I am no more worried about my health than usual.
1 I am worried about physical problems such as aches or pains, or upset stomach, or constipation.
2 I am very worried about physical problems and it's hard to think of much else.
3 I am so worried about my physical problems that I cannot think about anything else.
21. 0 I have not noticed any recent change in my interest in sex.
1 I am less interested in sex than I used to be.
2 I am much less interested in sex now.
3 I have lost interest in sex completely.

TOTAL

3.3 The Childhood Experience of Care and Abuse Questionnaire (CECA-Q)

FAMILY RELATIONSHIPS IN CHILDHOOD – CECA-Q - Questionnaire 4 -

1. WHO BROUGHT YOU UP BEFORE AGE 17

Please write below the *Parent Figures* who brought you up in childhood. List each family arrangement with different parent figures which lasted *one year or longer*. Consider natural parent, step-parent (including parent's live-in partner), aunt, friend of the family, adoptive parent, foster parent etc.

Fill in the first family arrangement below. For example, if this was with your natural parents, write in 'Mother' and 'Father' and age '0'; or if this was with just your mother write in 'Mother', leave the father column blank and age '0'

Family arrangement	Mother figure	Father figure	Your age at start
FIRST family	1a	1b	1c

If this was your *only* family up to the age of 17, then SKIP to the starred question below.

If you have lived in *more than just one* family arrangement, such as with mother and stepfather, then list them below, together with the age you were when the arrangement began.

Family arrangement	Mother figure	Father figure	Your age at start
SECOND family	1d	1e	1f
THIRD family	1g	1h	1i

**** Were you ever in a children's home or institution before age 17? YES NO**
(please circle the appropriate answer)

If 'YES' fill in the boxes below. If 'NO' skip to question 2 overleaf

TYPE OF INSTITUTION e.g. local authority care, hospital, boarding school	age when you started	age when you left
1.	1j	1k
2.	1l	1m

2. PARENTAL LOSS

Please circle the appropriate answers, and write in the age you were when it happened.

	MOTHER	FATHER
2a. Did either parent die before you were aged 17?	YES NO	YES NO
If YES, what age were you?	2b	2c

	MOTHER	FATHER
2d. Have you ever been separated from your parent for one year or more before the age of 17?	YES NO	YES NO

If YES, then fill in the boxes below; if NO then SKIP to question 3 overleaf.

	MOTHER	FATHER
At what age were you first separated?	2e	2f
How long was this separation, in years?	2g	2h
Please circle the reason for the separation:		
Parent's illness (2i)	YES NO	YES NO
Parent's work (2j)	YES NO	YES NO
Parents' divorce or separation (2k)	YES NO	YES NO
Abandoned by parent or never knew parent (2l)	YES NO	YES NO
Other reason (2m)	YES NO	YES NO

2n Please describe your experience

.....

.....

3. Please circle the appropriate numbers to describe your **Mother Figure**, as you remember her in **your first 17 years**. If you had more than one, choose the one you were with *the longest*, or the one you found *most difficult* to live with.

3a. Which mother figure are you describing below?

1. Natural mother
2. Step-mother/father's live-in partner
3. Other relative e.g. aunty, grandmother
4. Other non-relative e.g. foster mother, godmother
5. Other (describe).....

	Yes, definitely		Unsure		No, not at all
3b She was very difficult to please	1	2	3	4	5
3c She was concerned about my worries	1	2	3	4	5
3d She was interested in how I did at school	1	2	3	4	5
3e She made me feel unwanted	1	2	3	4	5
3f She tried to make me feel better when I was upset	1	2	3	4	5
3g She was very critical of me	1	2	3	4	5
3h She would leave me unsupervised before I was 10 years old	1	2	3	4	5
3i She would usually have time to talk to me	1	2	3	4	5
3j She would hit me	1	2	3	4	5
3k At times she made me feel I was a nuisance	1	2	3	4	5
3l She often picked on me unfairly	1	2	3	4	5
3m She was there if I needed her	1	2	3	4	5
3n She was interested in who my friends were	1	2	3	4	5
3o She was concerned about my whereabouts	1	2	3	4	5
3p She cared for me when I was ill	1	2	3	4	5
3q She neglected my basic needs (e.g. food and clothes)	1	2	3	4	5
3r She did not like me as much as my brothers and sisters (leave blank if no siblings)	1	2	3	4	5

Do you want to add anything about your mother?.....

.....

4. Please circle the appropriate numbers to describe **your Father Figure, as you remember him in your first 17 years**. If you had more than one, choose the one you were with *the longest*, or the one you found *most difficult* to live with.

4a. Which father figure are you describing below?

1. Natural father
2. Step-father/mother's live-in partner
3. Other relative e.g. uncle, grandfather
4. Other non-relative e.g. foster father, adoptive father
5. Other (describe).....

	Yes, definitely	Unsure			No, not at all
4b He was very difficult to please	1	2	3	4	5
4c He was concerned about my worries	1	2	3	4	5
4d He was interested in how I did at school	1	2	3	4	5
4e He made me feel unwanted	1	2	3	4	5
4f He tried to make me feel better when I was upset	1	2	3	4	5
4g He was very critical of me	1	2	3	4	5
4h He would leave me unsupervised before I was 10 years old	1	2	3	4	5
4i He would usually have time to talk to me	1	2	3	4	5
4j He would hit me	1	2	3	4	5
4k At times he made me feel I was a nuisance	1	2	3	4	5
4l He often picked on me unfairly	1	2	3	4	5
4m He was there if I needed him	1	2	3	4	5
4n He was interested in who my friends were	1	2	3	4	5
4o He was concerned about my whereabouts	1	2	3	4	5
4p He cared for me when I was ill	1	2	3	4	5
4q He neglected my basic needs (e.g. food and clothes)	1	2	3	4	5
4r He did not like me as much as my brothers and sisters (<i>leave blank if no siblings</i>)	1	2	3	4	5

Do you want to add anything about your father?.....

.....

5. CLOSE RELATIONSHIPS IN CHILDHOOD

(please circle as appropriate – if you circle NO to any question, SKIP the rest of that section and go on to the next one)

5a When you were a child or teenager, were there any ADULTS you could go to with your problems or to discuss your feelings?

YES NO

5b If YES: Who was that? (circle more than one if relevant)

1. mother / mother figure
2. father / father figure
3. other relative
4. family friend
5. teacher, vicar etc
6. other (describe)

5d Do you want to note anything about the relationship(s)?

5e Were there other CHILDREN/TEENAGERS your age that you could discuss your problems and feelings with?

YES NO

5/f If YES: Who was that? (circle more than one if relevant)

1. sister
2. brother
3. other relative
4. close friend
5. other less close friend(s)
6. other person (describe).....

5h Do you want to note anything about the relationship(s)?.....

5i Who would you describe as the TWO CLOSEST people to you as a child/teenager? (circle up to two)

1. mother / mother figure
2. father / father figure
3. sister or brother
4. other relative
5. family friend (adult)
6. friend your age
7. other (describe)

5j/c Do you want to note anything about the relationship(s)?.....

6. PHYSICAL PUNISHMENT BEFORE AGE 17 BY PARENT FIGURE OR OTHER HOUSEHOLD MEMBER - INTERVIEW

6a When you were a child or teenager were you ever hit repeatedly with an implement (such as a belt or stick) or punched, kicked or burnt by someone in the household?

YES NO

If YES, then fill in the boxes below; if NO then SKIP to question 7 overleaf.

	MOTHER FIGURE	FATHER FIGURE
How old were you when it began, in years?	6b	6c
Did the hitting happen on more than one occasion?	6d YES NO	YES NO
How often did the hitting happen?		
How old were you when the hitting stopped? How long did it go on for? How were you hit?	6e 1. belt or stick 2. punched/kicked 3. hit with hand 4. other	6f 1. belt or stick 2. punched/kicked 3. hit with hand 4. other
Were you ever injured e.g. bruises, black eyes, broken limbs?	6g YES NO	YES NO
Was this person so angry they seemed out of control?	6h YES NO	YES NO

Can you describe these experiences

.....
.....

Did you experience this from anyone else in the household? YES NO

If YES: describe your experiences.....

.....
.....

7. UNWANTED SEXUAL EXPERIENCES BEFORE AGE 17

(please circle as appropriate)

7a. When you were a child or teenager did you ever have any unwanted sexual experiences? YES NO UNSURE

7b. Did anyone force you or persuade you to have sexual intercourse against your wishes before age 17? YES NO UNSURE

7c. Can you remember any upsetting sexual experiences before age 17 with a related adult or someone in authority e.g. a teacher? YES NO UNSURE

If NO to all these, then SKIP to question 8 overleaf

If YES or UNSURE to any of them, then please complete the following questions:

	FIRST EXPERIENCE	SECOND EXPERIENCE
What age were you when it began (in years)?	7d	7e
Was the other person someone you knew?	7f YES NO	YES NO
How old was the other person?		
Was the other person a relative?	7g YES NO	YES NO
Did the other person live in your household?	7h YES NO	YES NO
Did this person do it to you on more than one occasion?	7i YES NO	YES NO
How often did it happen? How old were you when it stopped/how long did it go on for?		
Did it involve touching private parts of your body?	7j YES NO	YES NO
Did it involve touching private parts of the other person's body?	7k YES NO	YES NO
Did it involve sexual intercourse?	7l YES NO	YES NO

7l/c Can you describe these experiences?

.....

.....

8. YOUR CURRENT RELATIONSHIPS AND WORK

(Please circle or write in your answer – if you circle NO to any question, SKIP the rest of that section and go on to the next one)

8a. Do you have a partner? YES NO

If YES:

8b. Are you currently living with your partner?

- 0. No
- 1. Yes, cohabiting
- 2. Yes, married

8c. Does your partner work?

- 0. No
- 1. Student only
- 2. Part-time employment
- 3. Full-time employment

8d. What is your partner's job?

8e. Do you have children? YES NO EXPECTING FIRST BABY

If YES:

8f. How many children do you have?

8g. How many are currently living with you?

8h. How old is your eldest child?

8i. How old is your youngest child?

8j. Do any of your partner's children live with you YES NO
(i.e. your step-children)

8k. Are you currently employed?

- 0. No
- 1. Student only
- 2. Part-time employment
- 3. Full-time employment

8l. If YES, what is your job?

8m. Your gender: MALE FEMALE

8n. Your current age

Thank you for your help with this questionnaire. We realise that it is difficult to give a true picture of your childhood experience in a questionnaire, so if you have any comments you would like to add, please write them below. Your responses will be treated in the strictest confidence.

3.4 The Retrospective Bullying Questionnaire (RBQ)

RETROSPECTIVE BULLYING QUESTIONNAIRE - Questionnaire 3 -

The following questions are about bullying

- BULLYING IS INTENTIONAL HURTFUL BEHAVIOR
- IT CAN BE PHYSICAL OR PSYCHOLOGICAL
- IT IS OFTEN REPEATED AND CHARACTERIZED BY AN INEQUALITY OF POWER SO THAT IT IS DIFFICULT FOR THE VICTIM TO DEFEND HIM/HER SELF

ALL ANSWERS WILL BE TREATED CONFIDENTIALLY

Please think back to your school days. You may have seen some bullying at school, and you may have been involved in some way.

Tick the choice which best describes your own experiences at school

- I was not involved at all, and I never saw it happen ☐
- I was not involved at all, but I saw it happen sometimes ☐
- I would sometimes join in bullying others ☐
- I would sometimes get bullied by others ☐
- At various times, I was both a bully and a victim ☐

Can you briefly describe an incident in which you observed someone else being bullied or an incident in which you felt you were bullied?

PART ONE – PRIMARY SCHOOL

This part deals with your experiences at primary school (age 4 – 11 years)

1. Did you have a happy time at primary school?

- ☐ detested ☐ disliked ☐ neutral ☐ liked a bit ☐ liked a lot

2. Did you have a happy time at home with your family while in primary school?

- ☐ detested ☐ disliked ☐ neutral ☐ liked a bit ☐ liked a lot

The next questions are about physical forms of bullying – hitting, kicking, having things stolen from you

3. Were you physically bullied at primary school?

- hit/punched yes ☐ no ☐
stolen from yes ☐ no ☐

4. Did this happen...

- ☐ never ☐ rarely ☐ sometimes ☐ frequently ☐ constantly

5. How serious did you consider these bullying-attacks to be?

☐ I wasn't bullied ☐ not at all ☐ only a bit ☐ quite serious ☐ extremely serious

The next questions are about verbal forms of bullying – being called nasty names, being threatened

6. Were you verbally bullied at primary school?

called names yes ☐ no ☐
threatened yes ☐ no ☐

7. Did this happen...

☐ never ☐ rarely ☐ sometimes ☐ frequently ☐ constantly

8. How serious did you consider these bullying-attacks to be?

☐ I wasn't bullied ☐ not at all ☐ only a bit ☐ quite serious ☐ extremely serious

The next questions are about indirect forms of bullying – having lies or nasty rumours told about you behind your back, being deliberately excluded from social groups

9. Were you indirectly bullied at primary school?

had lies told about you yes ☐ no ☐
excluded yes ☐ no ☐

10. Did this happen...

☐ never ☐ rarely ☐ sometimes ☐ frequently ☐ constantly

11. How serious did you consider these bullying-attacks to be?

☐ I wasn't bullied ☐ not at all ☐ only a bit ☐ quite serious ☐ extremely serious

The next questions are about bullying in general

12. How long did the bullying attacks usually last?

☐ I wasn't bullied ☐ just a few days ☐ weeks ☐ months ☐ a year or more

13. How many pupils bullied you in primary school?

I wasn't bullied ☐
Mainly one boy ☐
Several boys ☐
Mainly one girl ☐
Several girls ☐
Both boys and girls ☐

14. If you were bullied, why do you think this happened?

PART TWO – SECONDARY SCHOOL/COLLEGE

This part deals with your experiences at secondary school and sixth form college (age 11 – 18)

15. Did you have a happy time at secondary school?

☐ detested ☐ disliked ☐ neutral ☐ liked a bit ☐ liked a lot

16. Did you have a happy time at home with your family while in secondary school?

☐ detested ☐ disliked ☐ neutral ☐ liked a bit ☐ liked a lot

The next questions are about physical forms of bullying – hitting, kicking, having things stolen from you

17. Were you physically bullied at secondary school?

hit/punched yes ☐ no ☐
stolen from yes ☐ no ☐

18. Did this happen...

☐ never ☐ rarely ☐ sometimes ☐ frequently ☐ constantly

19. How serious did you consider these bullying-attacks to be?

☐ I wasn't bullied ☐ not at all ☐ only a bit ☐ quite serious ☐ extremely serious

The next questions are about verbal forms of bullying – being called nasty names, being threatened

20. Were you verbally bullied at secondary school?

called names yes ☐ no ☐
threatened yes ☐ no ☐

21. Did this happen...

☐ never ☐ rarely ☐ sometimes ☐ frequently ☐ constantly

22. How serious did you consider these bullying-attacks to be?

☐ I wasn't bullied ☐ not at all ☐ only a bit ☐ quite serious ☐ extremely serious

The next questions are about indirect forms of bullying – having lies or nasty rumours told about you behind your back, being deliberately excluded from social groups

23. Were you indirectly bullied at secondary school?

had lies told about you yes ☐ no ☐
excluded yes ☐ no ☐

24. Did this happen...

☐ never ☐ rarely ☐ sometimes ☐ frequently ☐ constantly

25. How serious did you consider these bullying-attacks to be?

☐ I wasn't bullied ☐ not at all ☐ only a bit ☐ quite serious ☐ extremely serious

The next questions are about bullying in general

26. How long did the bullying-attacks usually last?

- ☐ I wasn't bullied ☐ just a few days ☐ weeks ☐ months ☐ a year or more

27. How many pupils bullied you in secondary school?

- ☐ I wasn't bullied
☐ Mainly one boy
☐ Several boys
☐ Mainly one girl
☐ Several girls
☐ Both boys and girls

28. If you were bullied, why do you think this happened?

PART THREE – GENERAL EXPERIENCES AT SCHOOL

29. Which were the main ways you used to cope with the bullying?
(Please tick one or more options)

- ☐ I wasn't bullied at school
☐ I tried to make fun of it
☐ I tried to avoid the situation
☐ I tried to ignore it
☐ I fought back
☐ I got help from friends
☐ I got help from a teacher
☐ I got help from family / parents
☐ I tried to handle it by myself
☐ I did not really cope
☐ Other Please specify:

30. Did you ever take part in bullying anyone while you were at school?
(Please tick one or more options)

- | | | | | |
|-----------------|-----|--------------------------|----|--------------------------|
| hit/punched | yes | <input type="checkbox"/> | no | <input type="checkbox"/> |
| stolen from | yes | <input type="checkbox"/> | no | <input type="checkbox"/> |
| called names | yes | <input type="checkbox"/> | no | <input type="checkbox"/> |
| threatened | yes | <input type="checkbox"/> | no | <input type="checkbox"/> |
| told lies about | yes | <input type="checkbox"/> | no | <input type="checkbox"/> |
| excluded | yes | <input type="checkbox"/> | no | <input type="checkbox"/> |

31. Did this happen...

- ☐ never ☐ rarely ☐ sometimes ☐ frequently ☐ constantly

32. How often did you try to avoid school by pretending to be sick or by playing truant because you were being bullied?

- I wasn't bullied at school ☐
Never ☐
Only once or twice ☐
Sometimes ☐
Maybe once a week ☐
Several times a week ☐

33. When you were being bullied, did you ever, even for a second, think about hurting yourself or taking your own life?

- I wasn't bullied at school ☐
No, never ☐
Yes, once ☐
Yes, more than once ☐

34. Have you been bullied since leaving school?

- I haven't been bullied since leaving school ☐
I have been bullied by my family ☐
I have been bullied by others (please specify): ☐

RECOLLECTIONS OF BEING BULLIED AT SCHOOL

(Only answer those questions if you were bullied):

35. Do you have vivid memories of the bullying event(s) which keep coming back causing you distress?

- ☐ no never ☐ not often ☐ sometimes ☐ often ☐ always

36. Do you have dreams or nightmares about the bullying event(s)?

- ☐ no never ☐ not often ☐ sometimes ☐ often ☐ always

37. Do you ever feel like you are re-living the bullying event(s) again?

- ☐ no never ☐ not often ☐ sometimes ☐ often ☐ always

38. Do you ever have sudden vivid recollections or 'flashbacks' to the bullying event(s)?

- ☐ no never ☐ not often ☐ sometimes ☐ often ☐ always

39. Do you ever feel distressed in situations which remind you of the bullying event(s)?

- ☐ no never ☐ not often ☐ sometimes ☐ often ☐ always

40. If you were bullied, do you feel it had any long-term effects? If so, please describe below:

The next questions are about bullying or harassment in the workplace

41. Have you ever experienced bullying in your workplace?

- I wasn't bullied in my workplace ☐
- I was bullied in one of my previous jobs ☐
- I was bullied in more than one of my previous jobs ☐
- I have been bullied in my present job ☐
- I have been bullied in all of my jobs ☐

42. Please state whether you have been bullied at work over the last six months?

- | | |
|--|---|
| No <input type="checkbox"/> | Yes, several times per month <input type="checkbox"/> |
| Yes, very rarely <input type="checkbox"/> | Yes, several times per week <input type="checkbox"/> |
| Yes, now and then <input type="checkbox"/> | Yes, almost daily <input type="checkbox"/> |

43. IF YES, when did the bullying start?

- | | |
|--|--|
| Within the last 6 months <input type="checkbox"/> | Between 6 and 12 months ago <input type="checkbox"/> |
| Between 1 and 2 years ago <input type="checkbox"/> | More than 2 years ago <input type="checkbox"/> |

44. IF you have been bullied, what did you do?

(Please tick one or more options)

- Tried to avoid the situation ☐
- Tried to ignore it ☐
- Confronted the bully ☐
- Went to the union/staff association ☐
- Went to personnel ☐
- Discussed it with colleagues ☐
- Went to occupational health ☐
- Went to the welfare department ☐
- Saw my doctor (GP) ☐
- I went for counselling ☐
- I got psychiatric help ☐
- Made use of the organisation's grievance procedure ☐
- I left the job ☐
- Did not really cope ☐
- Other ☐

THANK YOU VERY MUCH FOR YOUR CO-OPERATION

3.5 The Brief Life Event Questionnaire (BLEQ)

BRIEF LIFE EVENTS QUESTIONNAIRE – Questionnaire 5 -

The following questions are about events or problems which may have happened to you during the **last month, the last 6 months** (other than any in the last months) and in the **last 5 years** (other than any in the last 6 months) and might have caused you distress and to seek help.

- 1 Did you suffer from a serious illness, injury or an assault?**
- In the last month ☐ No ☐ Yes If yes, at that time, how bad was it for you?
☐ Very bad
☐ Moderately bad
☐ Not too bad
- In the last 6 months ☐ No ☐ Yes If yes, at that time, how bad was it for you?
☐ Very bad
☐ Moderately bad
☐ Not too bad
- Date: ☐ No ☐ Yes If yes, at that time, how bad was it for you?
☐ Very bad
☐ Moderately bad
☐ Not too bad
- In the last 5 years ☐ No ☐ Yes If yes, at that time, how bad was it for you?
☐ Very bad
☐ Moderately bad
☐ Not too bad
- Date: ☐ No ☐ Yes If yes, at that time, how bad was it for you?
☐ Very bad
☐ Moderately bad
☐ Not too bad
- 2 Did a serious illness, injury or assault happen to a close relative?**
- In the last month ☐ No ☐ Yes If yes, at that time, how bad was it for you?
☐ Very bad
☐ Moderately bad
☐ Not too bad
- In the last 6 months ☐ No ☐ Yes If yes, at that time, how bad was it for you?
☐ Very bad
☐ Moderately bad
☐ Not too bad
- Date: ☐ No ☐ Yes If yes, at that time, how bad was it for you?
☐ Very bad
☐ Moderately bad
☐ Not too bad
- In the last 5 years ☐ No ☐ Yes If yes, at that time, how bad was it for you?
☐ Very bad
☐ Moderately bad
☐ Not too bad
- Date: ☐ No ☐ Yes If yes, at that time, how bad was it for you?
☐ Very bad
☐ Moderately bad
☐ Not too bad
- 3 Did a parent, spouse (or partner), child, brother or sister of yours die?**
- In the last month ☐ No ☐ Yes If yes, at that time, how bad was it for you?
☐ Very bad
☐ Moderately bad
☐ Not too bad
- In the last 6 months ☐ No ☐ Yes If yes, at that time, how bad was it for you?
☐ Very bad
☐ Moderately bad
☐ Not too bad
- Date: ☐ No ☐ Yes If yes, at that time, how bad was it for you?
☐ Very bad
☐ Moderately bad
☐ Not too bad
- In the last 5 years ☐ No ☐ Yes If yes, at that time, how bad was it for you?
☐ Very bad
☐ Moderately bad
☐ Not too bad
- Date: ☐ No ☐ Yes If yes, at that time, how bad was it for you?
☐ Very bad
☐ Moderately bad
☐ Not too bad

- 4 Did a close family friend or other relative die, such as an aunt, cousin or grandparent?**
- In the last month ☐ No ☐ Yes If yes, at that time, how bad was it for you?
☐ Very bad
☐ Moderately bad
☐ Not too bad
- In the last 6 months ☐ No ☐ Yes If yes, at that time, how bad was it for you?
☐ Very bad
☐ Moderately bad
☐ Not too bad
- Date: ☐ No ☐ Yes If yes, at that time, how bad was it for you?
☐ Very bad
☐ Moderately bad
☐ Not too bad
- In the last 5 years ☐ No ☐ Yes If yes, at that time, how bad was it for you?
☐ Very bad
☐ Moderately bad
☐ Not too bad
- Date: ☐ No ☐ Yes If yes, at that time, how bad was it for you?
☐ Very bad
☐ Moderately bad
☐ Not too bad
- 5 Did you have a separation due to marital difficulties or break off a steady relationship?**
- In the last month ☐ No ☐ Yes If yes, at that time, how bad was it for you?
☐ Very bad
☐ Moderately bad
☐ Not too bad
- In the last 6 months ☐ No ☐ Yes If yes, at that time, how bad was it for you?
☐ Very bad
☐ Moderately bad
☐ Not too bad
- Date: ☐ No ☐ Yes If yes, at that time, how bad was it for you?
☐ Very bad
☐ Moderately bad
☐ Not too bad
- In the last 5 years ☐ No ☐ Yes If yes, at that time, how bad was it for you?
☐ Very bad
☐ Moderately bad
☐ Not too bad
- Date: ☐ No ☐ Yes If yes, at that time, how bad was it for you?
☐ Very bad
☐ Moderately bad
☐ Not too bad
- 6 Did you have serious problem with a close friend, neighbour or relatives?**
- In the last month ☐ No ☐ Yes If yes, at that time, how bad was it for you?
☐ Very bad
☐ Moderately bad
☐ Not too bad
- In the last 6 months ☐ No ☐ Yes If yes, at that time, how bad was it for you?
☐ Very bad
☐ Moderately bad
☐ Not too bad
- Date: ☐ No ☐ Yes If yes, at that time, how bad was it for you?
☐ Very bad
☐ Moderately bad
☐ Not too bad
- In the last 5 years ☐ No ☐ Yes If yes, at that time, how bad was it for you?
☐ Very bad
☐ Moderately bad
☐ Not too bad
- Date: ☐ No ☐ Yes If yes, at that time, how bad was it for you?
☐ Very bad
☐ Moderately bad
☐ Not too bad

- 7 Were you made redundant or sacked from your job?**
- | | | | |
|----------------------|-----------------------------|------------------------------|--|
| | <input type="checkbox"/> No | <input type="checkbox"/> Yes | If yes, at that time, how bad was it for you? |
| In the last month | | | <input type="checkbox"/> Very bad
<input type="checkbox"/> Moderately bad
<input type="checkbox"/> Not too bad |
| | <input type="checkbox"/> No | <input type="checkbox"/> Yes | If yes, at that time, how bad was it for you? |
| In the last 6 months | | | <input type="checkbox"/> Very bad
<input type="checkbox"/> Moderately bad
<input type="checkbox"/> Not too bad |
| Date: | | | |
| | <input type="checkbox"/> No | <input type="checkbox"/> Yes | If yes, at that time, how bad was it for you? |
| In the last 5 years | | | <input type="checkbox"/> Very bad
<input type="checkbox"/> Moderately bad
<input type="checkbox"/> Not too bad |
| Date: | | | |
- 8 Were you seeking work without success for more than 1 month?**
- | | | | |
|----------------------|-----------------------------|------------------------------|--|
| | <input type="checkbox"/> No | <input type="checkbox"/> Yes | If yes, at that time, how bad was it for you? |
| In the last month | | | <input type="checkbox"/> Very bad
<input type="checkbox"/> Moderately bad
<input type="checkbox"/> Not too bad |
| | <input type="checkbox"/> No | <input type="checkbox"/> Yes | If yes, at that time, how bad was it for you? |
| In the last 6 months | | | <input type="checkbox"/> Very bad
<input type="checkbox"/> Moderately bad
<input type="checkbox"/> Not too bad |
| | <input type="checkbox"/> No | <input type="checkbox"/> Yes | If yes, at that time, how bad was it for you? |
| In the last 5 years | | | <input type="checkbox"/> Very bad
<input type="checkbox"/> Moderately bad
<input type="checkbox"/> Not too bad |
- 9 Did you have a major financial crisis such as losing the equivalent of three months income?**
- | | | | |
|----------------------|-----------------------------|------------------------------|--|
| | <input type="checkbox"/> No | <input type="checkbox"/> Yes | If yes, at that time, how bad was it for you? |
| In the last month | | | <input type="checkbox"/> Very bad
<input type="checkbox"/> Moderately bad
<input type="checkbox"/> Not too bad |
| | <input type="checkbox"/> No | <input type="checkbox"/> Yes | If yes, at that time, how bad was it for you? |
| In the last 6 months | | | <input type="checkbox"/> Very bad
<input type="checkbox"/> Moderately bad
<input type="checkbox"/> Not too bad |
| Date: | | | |
| | <input type="checkbox"/> No | <input type="checkbox"/> Yes | If yes, at that time, how bad was it for you? |
| In the last 5 years | | | <input type="checkbox"/> Very bad
<input type="checkbox"/> Moderately bad
<input type="checkbox"/> Not too bad |
| Date: | | | |

- 10 Did you have problems with the police involving a court appearance?**
- In the last month ☐ No ☐ Yes If yes, at that time, how bad was it for you?
☐ Very bad
☐ Moderately bad
☐ Not too bad
- In the last 6 months ☐ No ☐ Yes If yes, at that time, how bad was it for you?
☐ Very bad
☐ Moderately bad
☐ Not too bad
- Date: ☐ No ☐ Yes If yes, at that time, how bad was it for you?
☐ Very bad
☐ Moderately bad
☐ Not too bad
- In the last 5 years ☐ No ☐ Yes If yes, at that time, how bad was it for you?
☐ Very bad
☐ Moderately bad
☐ Not too bad
- Date: ☐ No ☐ Yes If yes, at that time, how bad was it for you?
☐ Very bad
☐ Moderately bad
☐ Not too bad
- 11 Was something you valued lost or stolen?**
- In the last month ☐ No ☐ Yes If yes, at that time, how bad was it for you?
☐ Very bad
☐ Moderately bad
☐ Not too bad
- In the last 6 months ☐ No ☐ Yes If yes, at that time, how bad was it for you?
☐ Very bad
☐ Moderately bad
☐ Not too bad
- Date: ☐ No ☐ Yes If yes, at that time, how bad was it for you?
☐ Very bad
☐ Moderately bad
☐ Not too bad
- In the last 5 years ☐ No ☐ Yes If yes, at that time, how bad was it for you?
☐ Very bad
☐ Moderately bad
☐ Not too bad
- Date: ☐ No ☐ Yes If yes, at that time, how bad was it for you?
☐ Very bad
☐ Moderately bad
☐ Not too bad
- 12 Did you/your wife or partner give birth to a child?**
- In the last month ☐ No ☐ Yes If yes, at that time, how bad was it for you?
☐ Very bad
☐ Moderately bad
☐ Not too bad
- In the last 6 months ☐ No ☐ Yes If yes, at that time, how bad was it for you?
☐ Very bad
☐ Moderately bad
☐ Not too bad
- Date: ☐ No ☐ Yes If yes, at that time, how bad was it for you?
☐ Very bad
☐ Moderately bad
☐ Not too bad
- In the last 5 years ☐ No ☐ Yes If yes, at that time, how bad was it for you?
☐ Very bad
☐ Moderately bad
☐ Not too bad
- Date: ☐ No ☐ Yes If yes, at that time, how bad was it for you?
☐ Very bad
☐ Moderately bad
☐ Not too bad

Please use the space beneath to describe any other events that have occurred over the past that have had a significant effect on the way you feel.

In the last month...

At that time, how bad was it for you?

- ☐ Very bad
☐ Moderately bad
☐ Not too bad

In the past 6 months...

At that time, how bad was it for you?

- ☐ Very bad
☐ Moderately bad
☐ Not too bad

In the past 5 years...

At that time, how bad was it for you?

- ☐ Very bad
☐ Moderately bad
☐ Not too bad

3.6 The Perceived Stress Scale (PSS)

Perceived Stress Scale – Questionnaire 6 -

The questions in this scale ask you about your feelings and thoughts during the last month. In each case, please indicate with a check how often you felt or thought a certain way.

Although some of the questions are similar, there are differences between them and you should treat each one as a separate question. The best approach is to answer each question fairly quickly. That is, don't try to count up the number of times you felt a particular way, but rather indicate the alternative that seems like a reasonable estimate.

1. In the last month, how often have you been upset because of something that happened unexpectedly?
☐ 0=never ☐ 1=almost never ☐ 2=sometimes ☐ 3=fairly often ☐ 4=very often
2. In the last month, how often have you felt that you were unable to control the important things in your life?
☐ 0=never ☐ 1=almost never ☐ 2=sometimes ☐ 3=fairly often ☐ 4=very often
3. In the last month, how often have you felt nervous and "stressed"?
☐ 0=never ☐ 1=almost never ☐ 2=sometimes ☐ 3=fairly often ☐ 4=very often
4. In the last month, how often have you felt confident about your ability to handle your personal problems?
☐ 0=never ☐ 1=almost never ☐ 2=sometimes ☐ 3=fairly often ☐ 4=very often
5. In the last month, how often have you felt that things were going your way?
☐ 0=never ☐ 1=almost never ☐ 2=sometimes ☐ 3=fairly often ☐ 4=very often
6. In the last month, how often have you found that you could not cope with all the things that you had to do?
☐ 0=never ☐ 1=almost never ☐ 2=sometimes ☐ 3=fairly often ☐ 4=very often
7. In the last month, how often have you been able to control irritations in your life?
☐ 0=never ☐ 1=almost never ☐ 2=sometimes ☐ 3=fairly often ☐ 4=very often
8. In the last month, how often have you felt that you were on top of things?
☐ 0=never ☐ 1=almost never ☐ 2=sometimes ☐ 3=fairly often ☐ 4=very often
9. In the last month, how often have you been angered because of things that were outside of your control?
☐ 0=never ☐ 1=almost never ☐ 2=sometimes ☐ 3=fairly often ☐ 4=very often
10. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?
☐ 0=never ☐ 1=almost never ☐ 2=sometimes ☐ 3=fairly often ☐ 4=very often

3.7 The Multidimensional Scale of Perceived Social Support (MSPSS)

MULTIDIMENSIONAL SCALE OF PERCEIVED SOCIAL SUPPORT – Questionnaire 11 -
Zimet, Dahlem, Zimet & Farley, 1988

Instructions: We are interested in how you feel about the following statements
Read each statement carefully. Indicate how you feel about each statement

Circle the "1" if you Very Strongly Disagree

Circle the "2" if you Strongly Disagree

Circle the "3" if you Mildly Disagree

Circle the "4" if you are Neutral

Circle the "5" if you Mildly Agree

Circle the "6" if you Strongly Agree

Circle the "7" if you Very Strongly Agree

1. There is a special person who is around when I am in need.

Very Strongly Disagree	1	2	3	4	5	6	7	Very Strongly Agree
---------------------------	---	---	---	---	---	---	---	------------------------

2. There is a special person with whom I can share my joys and sorrows.

Very Strongly Disagree	1	2	3	4	5	6	7	Very Strongly Agree
---------------------------	---	---	---	---	---	---	---	------------------------

3. My family really tries to help me.

Very Strongly Disagree	1	2	3	4	5	6	7	Very Strongly Agree
---------------------------	---	---	---	---	---	---	---	------------------------

4. I get the emotional help and support I need from my family.

Very Strongly Disagree	1	2	3	4	5	6	7	Very Strongly Agree
---------------------------	---	---	---	---	---	---	---	------------------------

5. I have a special person who is a real source of comfort to me.

Very Strongly Disagree	1	2	3	4	5	6	7	Very Strongly Agree
---------------------------	---	---	---	---	---	---	---	------------------------

6. My friends really try to help me.

Very Strongly Disagree	1	2	3	4	5	6	7	Very Strongly Agree
---------------------------	---	---	---	---	---	---	---	------------------------

7. I can count on my friends when things go wrong.

Very Strongly Disagree	1	2	3	4	5	6	7	Very Strongly Agree
---------------------------	---	---	---	---	---	---	---	------------------------

8. I can talk about my problems with my family.

Very Strongly Disagree	1	2	3	4	5	6	7	Very Strongly Agree
---------------------------	---	---	---	---	---	---	---	------------------------

9. I have friends with whom I can share my joys and sorrows.

Very Strongly Disagree	1	2	3	4	5	6	7	Very Strongly Agree
---------------------------	---	---	---	---	---	---	---	------------------------

10. There is a special person in my life who cares about my feelings.

Very Strongly Disagree	1	2	3	4	5	6	7	Very Strongly Agree
---------------------------	---	---	---	---	---	---	---	------------------------

11. My family is willing to help me make decisions.

Very Strongly Disagree	1	2	3	4	5	6	7	Very Strongly Agree
---------------------------	---	---	---	---	---	---	---	------------------------

12. I can talk about my problems with my friends.

Very Strongly Disagree	1	2	3	4	5	6	7	Very Strongly Agree
---------------------------	---	---	---	---	---	---	---	------------------------

The items tended to divide into factor groups relating to the source of the social support, namely family (Fam), friends (Fri) or significant other (SO).

1. SO
2. SO
3. Fam
4. Fam
5. SO
6. Fri
7. Fri
8. Fam
9. Fri
10. SO
11. Fam
12. Fri

Significant other score :

Family score :

Friends score :

Sum score :

3.8 The Significant Other Scale (SOS)

SOS

name: _____

date: _____

Please list below people who are important in your life. Possible relationships include friends, partner, mother, father, children, brothers, sisters, other relatives, work colleagues, and so on. For each person you list, circle a number from 1 to 7 to show how well they provide the type of help listed. The second part of each question asks you to rate how you would like things to be if they were exactly as you would most hope for. Again circle a number from 1 to 7 to show what rating this would involve. Use further *Significant Others Scale* sheets if appropriate.

name/relationship:		never		sometimes			always	
1	a can you trust, talk to frankly and share feelings with this person?	1	2	3	4	5	6	7
	b what rating would your ideal be?	1	2	3	4	5	6	7
2	a can you lean on and turn to this person in times of difficulty?	1	2	3	4	5	6	7
	b what rating would your ideal be?	1	2	3	4	5	6	7
3	a do they give you practical help?	1	2	3	4	5	6	7
	b what rating would your ideal be?	1	2	3	4	5	6	7
4	a can you spend time with them socially?	1	2	3	4	5	6	7
	b what rating would your ideal be?	1	2	3	4	5	6	7

name/relationship:		never		sometimes			always	
1	a can you trust, talk to frankly and share feelings with this person?	1	2	3	4	5	6	7
	b what rating would your ideal be?	1	2	3	4	5	6	7
2	a can you lean on and turn to this person in times of difficulty?	1	2	3	4	5	6	7
	b what rating would your ideal be?	1	2	3	4	5	6	7
3	a do they give you practical help?	1	2	3	4	5	6	7
	b what rating would your ideal be?	1	2	3	4	5	6	7
4	a can you spend time with them socially?	1	2	3	4	5	6	7
	b what rating would your ideal be?	1	2	3	4	5	6	7

name/relationship:		never		sometimes			always	
1	a can you trust, talk to frankly and share feelings with this person?	1	2	3	4	5	6	7
	b what rating would your ideal be?	1	2	3	4	5	6	7
2	a can you lean on and turn to this person in times of difficulty?	1	2	3	4	5	6	7
	b what rating would your ideal be?	1	2	3	4	5	6	7
3	a do they give you practical help?	1	2	3	4	5	6	7
	b what rating would your ideal be?	1	2	3	4	5	6	7
4	a can you spend time with them socially?	1	2	3	4	5	6	7
	b what rating would your ideal be?	1	2	3	4	5	6	7

please turn over

name/relationship:		never		sometimes			always	
1	a can you trust, talk to frankly and share feelings with this person?	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>	<i>6</i>	<i>7</i>
	b what rating would your ideal be?	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>	<i>6</i>	<i>7</i>
2	a can you lean on and turn to this person in times of difficulty?	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>	<i>6</i>	<i>7</i>
	b what rating would your ideal be?	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>	<i>6</i>	<i>7</i>
3	a do they give you practical help?	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>	<i>6</i>	<i>7</i>
	b what rating would your ideal be?	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>	<i>6</i>	<i>7</i>
4	a can you spend time with them socially?	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>	<i>6</i>	<i>7</i>
	b what rating would your ideal be?	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>	<i>6</i>	<i>7</i>

name/relationship:		never		sometimes			always	
1	a can you trust, talk to frankly and share feelings with this person?	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>	<i>6</i>	<i>7</i>
	b what rating would your ideal be?	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>	<i>6</i>	<i>7</i>
2	a can you lean on and turn to this person in times of difficulty?	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>	<i>6</i>	<i>7</i>
	b what rating would your ideal be?	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>	<i>6</i>	<i>7</i>
3	a do they give you practical help?	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>	<i>6</i>	<i>7</i>
	b what rating would your ideal be?	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>	<i>6</i>	<i>7</i>
4	a can you spend time with them socially?	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>	<i>6</i>	<i>7</i>
	b what rating would your ideal be?	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>	<i>6</i>	<i>7</i>

name/relationship:		never		sometimes			always	
1	a can you trust, talk to frankly and share feelings with this person?	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>	<i>6</i>	<i>7</i>
	b what rating would your ideal be?	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>	<i>6</i>	<i>7</i>
2	a can you lean on and turn to this person in times of difficulty?	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>	<i>6</i>	<i>7</i>
	b what rating would your ideal be?	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>	<i>6</i>	<i>7</i>
3	a do they give you practical help?	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>	<i>6</i>	<i>7</i>
	b what rating would your ideal be?	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>	<i>6</i>	<i>7</i>
4	a can you spend time with them socially?	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>	<i>6</i>	<i>7</i>
	b what rating would your ideal be?	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>	<i>6</i>	<i>7</i>

name/relationship:		never		sometimes			always	
1	a can you trust, talk to frankly and share feelings with this person?	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>	<i>6</i>	<i>7</i>
	b what rating would your ideal be?	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>	<i>6</i>	<i>7</i>
2	a can you lean on and turn to this person in times of difficulty?	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>	<i>6</i>	<i>7</i>
	b what rating would your ideal be?	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>	<i>6</i>	<i>7</i>
3	a do they give you practical help?	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>	<i>6</i>	<i>7</i>
	b what rating would your ideal be?	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>	<i>6</i>	<i>7</i>
4	a can you spend time with them socially?	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>	<i>6</i>	<i>7</i>
	b what rating would your ideal be?	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>	<i>6</i>	<i>7</i>

emotional support: actual av.____ ideal av.____ ; **practical support:** actual av.____ ideal av.____

3.9 Coding Procedure

Current symptoms

The Prodromal Questionnaire

The Prodromal Questionnaire (PQ) is a 92-item instrument developed by Loewy and colleagues (2005) as a self-report screening measure for people at high clinical risk for psychosis. The instrument includes adapted items from the Schizotypal Personality Questionnaire (SPQ; Raine, 1991) and probe questions from a structured clinical interview for the ascertainment of people at high risk of developing psychosis (the Structured Interview for Prodromal Syndromes, SIPS; Miller, et al., 1999). Initial validation of the instrument in a high risk sample demonstrated good concurrent validity with the SIPS, with a score of eight or more positive symptoms predicting high risk status with 90 per cent sensitivity and 49 per cent specificity, while a score of at least 14 positive symptoms improved specificity to 81 per cent with a reduction in sensitivity of 18 per cent (Loewy, et al., 2005). There are four symptom subscales: positive symptoms, negative symptoms, disorganised symptoms, and general/affective symptoms. The positive subscale comprises items assessing unusual thinking, perceptual abnormalities, and cognitive disorganisation.

In the present study, participants indicated whether or not they have experienced each item within the last month by circling either 'true' or 'false'. The number of true responses was summed to give a score for attenuated symptoms for each of the four symptom subscales. The total scores on the positive, negative, and disorganised subscales were then summed to give an overall attenuated psychotic symptoms score.

The Beck Depression Inventory

The BDI-II (Beck, et al., 1996) is a widely used 21-item self-report instrument assessing severity of a number of symptoms of depression.

In the present study, participants selected the response which best describes how they had felt in the last two weeks for each of the 21 -items. The response for each item was scored on a scale of zero to three and the summed scores over all items gave a total score for current depressive symptoms.

Early adverse and traumatic experiences

Exposure to early adverse or traumatic experiences was assessed using the Childhood Experience of Care and Abuse Questionnaire (CECA-Q; Bifulco, et al., 2005), which was administered as a semi-structured interview, and the Retrospective Bullying Questionnaire (RBQ; Schafer, et al., 2004), which was administered as a self-report questionnaire.

Participants were asked about 16 indicators of stressful life events or adversity that could have occurred before the age of 17:

- disrupted living arrangements
- being taken into local authority care
- death of mother figure
- death of father figure
- separation from mother figure
- separation from father figure
- perceived neglect from mother figure
- perceived neglect from father figure
- perceived antipathy from mother figure
- perceived antipathy from father figure
- lack of supportive figures
- severe physical abuse from mother figure
- severe physical abuse from father figure
- severe sexual abuse
- severe bullying during primary school
- severe bullying during secondary school

For each item, participants were coded for 'exposure' (1) or 'no exposure' (0). Participants were told to consider the term 'parent figure' to include natural parents, step- parents (including parent's live-in partner), adoptive parents, foster parents, family members, friend of the family etc.

Disrupted living arrangements

At the start of the CECA-Q interview, a timeline of living arrangements was constructed, starting with the mother and father figures present in the family home at birth and then identifying the start point, duration, and nature of any changes that occurred until the participant was 17 years old. For example, if the participant lived in the same household with the same mother and father figures for the entire 17 year period, then this was considered one living arrangement. If, for example, the participant's mother and father separated when the participant was eight years old, he or she then lived with only the mother in the family house until the mother's new partner moved in at age 14, and the family arrangement remained this way until he or she was 17, then this would be considered three family arrangements, lasting eight, six, and three years, respectively. The total number of different arrangements within the family home which lasted longer than 12 months was counted for each participant. The cut-off employed by Fisher and colleagues (2010) was applied to produce a dichotomous variable of exposure to disrupted living arrangements, with participants with one or two arrangements being assigned to the no exposure category (0) and those with a total arrangements score of three or more assigned to the exposure category (1).

Parental death and separation

Participants were asked the question "Have you ever been separated from your parent for one or more years before the age of 17?" For each separation, the reason for the separation, its duration, and the age at which it occurred were determined by further questioning. Exposure to separation (1) was considered to have occurred if the participant experienced any separations lasting more than 12 months, while participants who experienced no separations or separations lasting less than 12 months were assigned to the no exposure category (0). Participants were also asked "Did either parent die before you were aged 17?" Death of a parent figure was coded as exposure (1) and no death of the parent figure was coded as no exposure (0). Exposure to separation from and death of parent figure were determined separately for mother figures and father figures.

Local authority care

Participants were asked the question “Were you ever in a children's home or other institution, such as local authority care, hospital, or boarding school, before age 17?” Any participants who answered ‘yes’ were asked what kind of institution this was, how many times they ever lived in such an institution, the duration of the stay and the age at which they lived in each institution. Participants reporting any time spent in local authority care environments were assigned to the exposure to local authority care category (1), while those who did not spend time in care, or were separated from the family home through hospital stays or boarding school were coded as no exposure (0).

Lack of supportive figures

Participants were asked two questions about the presence of supportive figures in their lives before the age of 17: “When you were a child or teenager, were there any adults you could go to with your problems or to discuss your feelings?” and “Were there other children or teenagers your age that you could discuss your problems and feelings with?” A negative response to both questions was coded as exposure to lack of supportive figures (1), while a positive response to either question was coded as no exposure to lack of supportive figures (0).

Neglect and antipathy

Exposure to neglect and antipathy was assessed by asking the participant to complete a 16 item questionnaire about the relationship they had with each parent figure up until the age of 17. When participants had lived with more than one mother or father figure, they were asked to complete the questionnaire regarding the parent figure with whom they had lived the longest or found it most difficult to live. Neglect was assessed in terms of the parent figure’s disinterest in material care: feeding and clothing, health, schoolwork, and friendships etc. An example neglect question is “She was concerned about my whereabouts.” Antipathy was assessed as hostility, coldness, or rejection shown to the child by parent figures, including ‘scapegoating’ behaviour, and an example antipathy question is “He made me feel unwanted.” Each questionnaire contained 16 items: eight neglect items and eight antipathy items. The participant

indicated the extent to which each antipathy and neglect item occurred within his or her relationships with father and mother figures by circling a number on a five point scale (1= 'no, not at all' to 5= 'yes, definitely'). Exposure to severe maternal neglect (1) was indicated by a score of 25 or more while exposure to severe paternal neglect (1) was indicated by a score of 26 or more on the neglect items. Exposure to severe maternal antipathy (1) was defined as a score of 28 or more and exposure to severe paternal antipathy (1) was defined as a score of 30 or more on the antipathy items. These scores are the severity cut-offs recommended by Bifulco et al. (2005) and scores less than these cut- offs were coded as no exposure (0).

Physical abuse

Exposure to physical abuse was assessed by asking the participant the following screening question: "When you were a child or teenager, were you ever hit repeatedly with an implement (such as a belt or stick), or punched, kicked or burnt by someone in the household?" Participants who responded 'yes' to this question were then asked further questions to determine the nature of the abuse. In addition to information about the age of onset and offset of abuse, participants were asked questions to assess the severity of abuse, a point given for each positive response: whether it happened on more than one occasion (1), whether they were hit using a 'severe' method (i.e., with a belt or stick, or punched or kicked, or hit in some other severe way, as opposed to hitting with hand or slapping) (1), whether the abuse resulted in injury (e.g., bruises, black eyes, broken limbs) (1), and whether the person hitting them seemed 'out of control' (1). A score of at least three for these items was considered to indicate exposure to severe physical abuse (1), i.e., the abuse involved repeated attacks where implements such as belts or sticks were used, or punching or kicking occurred, with the possibility of causing harm (Bifulco, et al., 2005). Participants answering 'no' to the screening question or scoring less than three to the severity questions were coded as no exposure to severe physical abuse (0). Experiences of maternal and paternal physical abuse were coded separately.

Sexual abuse

Exposure to sexual abuse was assessed by asking the participant three screening questions: “When you were a child or teenager did you have any unwanted sexual experiences?”, “Did anyone force you or persuade you to have sexual intercourse against your wishes before age 17?”, and “Can you think of any upsetting sexual experiences before age 17 with a related adult or someone in authority, for example, a teacher?” When more than one experience was disclosed, participants were asked about the earliest experience and the most severe subsequent experience. To determine the presence and assess the severity of sexual abuse, further questions regarding the nature of the experiences were asked of participants who gave responses of ‘yes’ or ‘unsure’ to any screening question, with a point given for each positive response. Specifically, participants were asked whether the abuse occurred on more than one occasion (1), whether they knew the perpetrator (1), whether the perpetrator was a relative (1), whether the perpetrator lived in the same household (1), and whether the abuse involved touching of the participant’s private parts (1), touching of the perpetrator’s private parts (1), and/or sexual intercourse (1). Exposure to severe sexual abuse (1) was considered to have occurred when a participant’s severity score was at least two (Bifulco, et al., 2005). Participants who answered ‘no’ to all three screening questions or whose severity score was less than two were assigned to the no exposure to severe abuse category (0).

Bullying

Exposure to physical (being hit, punched, or stolen from), verbal (being called names or threatened), and indirect (being excluded or having had lies told about you) bullying during primary school and secondary school was assessed by asking the participant how often each of these experiences occurred (‘never’ = 0, ‘rarely’ = 1, ‘sometimes’ = 2, ‘frequently’ = 3, ‘constantly’ = 4) and how serious he or she considered them to be (‘I wasn’t bullied’ = 0, ‘not at all’ = 1, ‘only a bit’ = 2, ‘quite serious’ = 3, ‘extremely serious’ = 4). Exposure to severe bullying (1) was considered to have occurred when participants reported frequency scores of three or four (frequent to constant bullying) as well as seriousness scores of three or four (quite to extremely serious bullying) in any of the three bullying domains (Schafer, et al., 2004). Participants with frequency

and seriousness scores of less than three, or with either the frequency or seriousness score less than three were coded as no exposure to severe bullying (0). Exposure was determined separately for experiences of bullying at primary school and secondary school, and participants who were bullied at both primary and secondary school were additionally identified as 'stable' victims (Schafer, et al., 2004).

Early adverse and traumatic experience score

Each early adverse or traumatic experience assessed was coded as a dichotomous variable ('no exposure' 0 vs. 'exposure' 1) according to the definitions of exposure defined above. The total number of exposures to these experiences was calculated to produce the 'early adverse and traumatic experiences score', which had a minimum of zero (no exposure to any adverse or traumatic experience) and a maximum of 16 (exposure to every adverse or traumatic experience assessed). The term 'early adverse and traumatic experiences' was chosen in order to reflect that a broader range of stressful experiences considered to be 'adverse' were assessed than in previous studies (for example, prolonged separation from parent figures and severe bullying) but that these experiences also included the more severe 'traumatic experiences' like physical and sexual abuse that are usually investigated. The total score gives an indication of the overall exposure to adversity experienced by each participant during childhood and early adolescence. The early adverse and traumatic experience score was transformed into a dichotomous variable with scores of zero being coded as no exposure to early adverse or traumatic experiences (0) and scores of one or more being coded as exposure to early adverse or traumatic experiences (1).

Recent stressful life events

The Brief Life Event Questionnaire

The Brief Life Event Questionnaire (BLEQ) assesses exposure to 12 potentially stressful or threatening life events over the past six months: a serious illness, injury, or assault to the participant (1); a serious illness, injury, or assault to a close relative (2); the death of a parent, partner, or sibling (3); the death of a close family friend or other relative (4); the end of a steady relationship or marital separation (5); a serious problem with a close friend, neighbour, or relative (6); being made redundant or

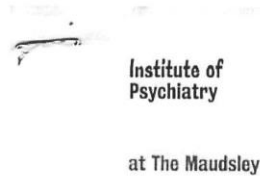
sacked (7); seeking work without success for more than one month (8); a major financial crisis (9); problems with the police involving a court appearance (10); the theft of a valued item (10); and the participant/partner giving birth to a child (12). Participants indicated 'yes' or 'no' for each item by ticking a box. A dichotomous variable was constructed for each of the 12 life events, with 'yes' responses indicating exposure to the event coded as one and 'no' responses indicating no exposure coded as zero. A total life event score was calculated by summing the total number of stressful life events to which each participant was exposed in the previous six months, giving a range of zero to 12. A further dichotomous variable was then constructed from the total life event score to indicate exposure to any stressful life event (total score of one or more) or no exposure to any stressful life event (total score of zero) for the past six months.

For each reported life event, participants were asked to rate how bad the event was for them ('not too bad', 'moderately bad', or 'very bad'). Each life event was categorised as being an 'independent' life event, i.e., an event which is outside of an individual's control or unlikely to be influenced by his or her actions, or a 'dependent' life event, i.e., an event which is influenced by an individual's actions or within his or her control. Items 5, 6, 7, 8, 9, 10, and 12 were coded as dependent life events, while items 1, 2, 3, 4, and 11 were coded as independent life events. The total independent and the total dependent life event scores were calculated by summing the total number of exposures to the relevant life events.

The Perceived Stress Scale

The Perceived Stress Scale (PSS) assesses how often participants experience general feelings of stress or inability to cope over the past month. There are ten items, four of which are reverse coded. Participants indicated by ticking a box the frequency of each feeling ('never', 'almost never', 'sometimes', 'fairly often', 'very often'). These frequencies corresponded to scores of zero to four (or four to zero, for the reverse scored items), and the scores were summed to give a total perceived stress score out of 40.

Appendix 4: Ethical Approval



Ethical Committee
(Research)
Research Ethics Co-ordinator
Margaret M Chambers Msc

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De Crespigny Park
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London SE5 8AF
Tel 020 7848 0797
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ETHICAL COMMITTEE (RESEARCH)

16 May 2003

Prof P McGuire
Psychological Medicine
Institute of Psychiatry

Dear Prof McGuire

Re: Salivary cortisol in people with prodromal symptoms (013/03)

The Chair of the Ethical Committee (Research) has taken action to approve this study from an ethical point of view.

Please note that this approval is subject to confirmation by the full Committee when it meets on 20 June 2003. Initial approval is given for one year. This will be extended automatically only on completion of annual progress reports on the study when requested by the EC(R). Please note that as Principal Investigator you are responsible for ensuring these reports are sent to us.

Please note that projects which have not commenced within two years of original approval must be re-submitted to the EC(R).

Any serious adverse events which occur in connection with this study should be reported to the Committee using the attached form.

Please quote Study No. 013/03 in all future correspondence.

Yours sincerely,

Margaret M Chambers
Research Ethics Coordinator

www.kcl.ac.uk

**Institute of
Psychiatry**

at The Maudsley

Ethical Committee
(Research)
Research Ethics Co-ordinator
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University of London

ETHICAL COMMITTEE (RESEARCH)

30 June 2003

Prof P McGuire
Psychological Medicine
Institute of Psychiatry

Dear Prof McGuire

Re: Salivary cortisol in people with prodromal symptoms (013/03)

At its meeting on 20 June 2003, the Ethical Committee (Research) considered and confirmed Chair's action to approve Study No 013/03, from an ethical point of view.

Yours sincerely

Margaret M Chambers
Research Ethics Co-ordinator

www.kcl.ac.uk

London, 07/09/2015

To Whom It May Concern,

The attached ethical approval was granted in 2003 for the original study "Cortisol in people with prodromal symptoms" (Study Number 013/03). A Notice of Substantial Amendment was submitted to the joint Research Ethics Committee detailing proposed changes to the study protocol to allow assessment of stressful and traumatic events through use of additional instruments. Favorable opinion of the amendment was granted in 2005 by the Research Ethics Committee.

Unfortunately due to staff changes and office moves we can not longer find the original copy of the amendment letter. The study was originally reviewed by the SLaM IOP ethics committee. I have been advised by our research governance office that this committee no longer exists and now comes under the Camberwell and St Giles NRES Committee London. I have contacted them to ask whether they have a formal record somewhere of ethical approval. Unfortunately, that is no longer the case.

However, please note that from 2008 participants were recruited as part of the study "The Impact of early adverse experiences on the vulnerability for psychosis" (REC reference number 08/H0722/45). A copy of the approval is also attached.

Yours sincerely,



Dr Lucia Valmaggia

National Research Ethics Service

Camden & Islington Community Local Research Ethics Committee

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NW1 0PE

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14 July 2008

Dr Lucia R. Valmaggia
Peggy Pollak Research Fellow/Clinical Lecturer
Institute of Psychiatry, KCL
Dept of Psychological Medicine, PO 67
De Crespigny Park
London
SE5 8AF

Dear Dr Valmaggia

Full title of study: The impact of early adverse experiences on the vulnerability for psychosis

REC reference number: 08/H0722/45

Thank you for your letter of 04 July 2008, responding to the Committee's request for further information on the above research and submitting revised documentation, subject to the conditions specified below.

The further information was considered at the meeting of the Sub-Committee of the REC held on 09 July 2008. A list of the members who were present at the meeting is attached.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

The Committee has not yet been notified of the outcome of any site-specific assessment (SSA) for the research site(s) taking part in this study. The favourable opinion does not therefore apply to any site at present. We will write to you again as soon as one Research Ethics Committee has notified the outcome of a SSA. In the meantime no study procedures should be initiated at sites requiring SSA.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

This Research Ethics Committee is an advisory committee to London Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England

CAM487

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission at NHS sites ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Application		28 April 2008
Investigator CV	C.I.s CV - Lucia Valmaggia	30 April 2008
Protocol	Version 1	30 April 2008
Summary/Synopsis	Version 1	30 April 2008
Interview Schedules/Topic Guides	Post VR interview guide - Version 1	30 April 2008
Questionnaire: Perceived Stress Scale	Version 1	30 April 2008
Questionnaire: Brief Life Events Questionnaire	Version 1	30 April 2008
Questionnaire: Family Relationships in Childhood - CECA-Q	Version 1	30 April 2008
Questionnaire: Retrospective Bullying Questionnaire	Version 1	30 April 2008
Questionnaire: OASIS SF Scale	Version 1	30 April 2008
Questionnaire: Achievement - Expectation Scale	Version 1	30 April 2008
Questionnaire: Defeat Scale (SDS)	Version 1	30 April 2008
Questionnaire: Entrapment Scale (SES)	Version 1	30 April 2008
Questionnaire: Social Comparison Scale	Version 1	30 April 2008
Questionnaire: Perceived Ethnic Discrimination Questionnaire - Community Version	Version 1	30 April 2008
Questionnaire: Post VR VAS Scales	Version 1	30 April 2008
Questionnaire: SSPS	Version 1	30 April 2008
Questionnaire: IPSM		30 April 2008
Questionnaire: DASS	Version 1	30 April 2008
Questionnaire: Multidimensional Scale of Perceived Social Support	Version 1	30 April 2008
Participant Information Sheet: For participants	Version 2	04 July 2008
Participant Information Sheet: For control participants	Version 2	04 July 2008
Participant Consent Form: For participants	Version 2	04 July 2008
Participant Consent Form: For control participants	Version 2	04 July 2008
Response to Request for Further Information		04 July 2008
Virtual reality study of paranoid thinking in the general population	D. Freeman et al.	01 January 2008
'Studying and treating schizophrenia using virtual reality; A new paradigm'	D. Freeman	28 March 2008
'Virtual reality and paranoid ideations in people with an 'at-risk mental state' for psychosis'	Valmaggia et al.	01 January 2007

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

08/H0722/45

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely



Ms Stephanie Ellis
Chair

Email: katherine.ouseley@camdenpct.nhs.uk

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments

"After ethical review – guidance for researchers"

Copy to: Sponsor and Research Governance contact:

*Mrs Gill Lambert
Research Governance/ Clinical Trials Facilitator
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De Crespigny Park, Denmark Hill
London, SE5 8AF*

Camden & Islington Community Local Research Ethics Committee

Attendance at Sub-Committee of the REC meeting on 09 July 2008

Committee Members:

<i>Name</i>	<i>Profession</i>
Ms Stephanie Ellis (CHAIR)	Former Civil Servant
Professor David Caplin	Senior Research Investigator, Professor of Physics

Service Evaluation

An audit of the assessment process in a National and Specialist CAMHS service and the development of a compulsory assessment package for clinical use

Ukwuori-Gisela Kalu

Supervised by Dr Rhianna Watts

King's College London
Institute of Psychiatry, Psychology and Neuroscience
Department of Psychology

Abstract

As a relatively new service, the assessment package offered by the National and Specialist Child and Adolescent Forensic Psychology Service is currently based on the individual needs of the young people referred and no standard assessment package is offered. The advantages of offering individually tailored assessment packages include the retention of difficult to engage individuals and the provision of concise reports in a timely and responsive manner. However, the relative absence of common measures across the client group prevents exploration of client group profiles and therefore limits the ability to ensure that assessments offered are compliant with current national governance targets and/or evidence based assessment.

This service evaluation sought to audit the current assessment process of the National and Specialist Child and Adolescent Forensic Psychology Service, in order to establish compliance with national governance. This evaluation further sought to establish the level of referrer satisfaction, and where non-compliance with national governance and/or referrer dissatisfaction was evident, recommendations for the improvement of the service's current assessment process were suggested.

Completed referrals for assessment (up to December 2012) were identified and examined. National guidelines relevant to the client population were also identified and examined, and results of these two parts were compared to establish service compliance. In addition, a service specific referrer satisfaction questionnaire was developed and qualitative feedback from referrers obtained.

Results show that service compliance with *required* assessment parts (as identified through the review of national guidelines) was high, but service compliance with *required* assessment domains and measures (as identified through the review of national guidelines) was low. High levels of referrer satisfaction were also revealed. Where evidence of non-compliance was found, recommendations for the improvement of the service's current assessment process were made and a compulsory basic assessment package was developed for future clinical use.

Table of Contents

Introduction	184
The National and Specialist Child and Adolescent Forensic Psychology Service	184
Rational	185
Aims	186
 PART I a: An audit of the service's current assessment process	187
METHOD	187
Design	187
Procedure	187
RESULTS	187
Demographics	187
Reasons for referral	188
Assessment parts	188
Assessment domains and measures	190
 PART I b: Compliance with national governance targets	193
METHOD	193
Design	193
Procedure	193
RESULTS	194
Establishing Service Compliance	198
Service compliance with <i>required</i> and <i>desirable</i> Assessment Parts	199
Service compliance with <i>required</i> and <i>desirable</i> Assessment Domains	201
Service compliance with <i>required</i> and <i>desirable</i> Assessment Measures	206
CONCLUSION	206
RECOMMENDATIONS	207
 PART II: Referrer satisfaction	210
METHODS	210
Design	210
Procedure	210

RESULTS.....	211
CONCLUSION.....	215
RECOMMENDATIONS.....	216
 Discussion	 219
Summary of recommendations	219
Limitations.....	219
Conclusion.....	220
Dissemination & Leadership	221
 References	 222
 Appendices	 225
Appendix 1: Ethical Approval	225
Appendix 2: List of all standardized measures used by the service	231
Appendix 3: A brief summary of each national governance guideline.....	233
Appendix 4: The newly developed compulsory assessment package	248

List of Figures and Tables

Figure 1 Assessment requests received and completed by the service.....	188
Figure 2 Assessment parts of completed assessments by the service.....	189
Figure 3 Standardized assessment measures employed by the service.....	192
Figure 4 Review of national governance targets.	194
Figure 5 Reported responses on the quality of the service received.....	213
Figure 6 Reported reasons for referral to and assessments provided	214
Table 1 Domains addressed in the service’s current assessment process.....	191
Table 2 Required and desirable assessment parts	195
Table 3 Required and desirable assessment domains.....	196
Table 4 Required and desirable assessment domains continued	197
Table 5 Required and desirable assessment measures.....	198
Table 6 Compliance percentages	199
Table 7 Service Compliance with required Assessment Parts.....	200
Table 8 Service compliance with the desirable Assessment Parts	201
Table 9 Service compliance with the required Assessment Domains.....	203
Table 10 Service compliance with the desirable Assessment Domains	205

Introduction

The National and Specialist Child and Adolescent Forensic Psychology Service

The National and Specialist Child and Adolescent Forensic Psychology Service was established in 2011. It provides an assessment and intervention service for young people between the ages of 10 and 17 years who have committed, or present significant risk of, serious violence, fire-setting, or sexually harmful behaviour. These young people often experience mental health problems such as conduct disorder, attention deficit hyperactivity disorder (ADHD), emerging anti-social or borderline personality disorder, self-harm, post-traumatic stress disorder (PTSD), substance misuse or developmental disorders such as autistic spectrum disorder (ASD) alongside their offending behaviour. In addition, they are likely to experience psychosocial difficulties and are often looked after, subject to child protection plans, have parents with mental health problems, do not attend school, and/or belong to a gang.

Referrals to the service come from a variety of sources including mental health professionals within local and national CAMHS teams, Youth Offending Teams (YOT), Social Services, Solicitors and the Courts. The reasons for referral differ according to the young person's presentation, situation and the referral source. However, commonalities include requests for a structured forensic risk assessment and guidance as to intervention and or sentencing needs.

The service provides complex assessments which include 1) forensic risk assessments, 2) offence related assessments (i.e. an assessment to determine whether a mental health difficulty or cognitive impairment have contributed to the young person committing an offence), 3) Court assessments (i.e. an assessment of the young person's ability to understand and participate in the trial process), 4) diagnostic mental health assessments, 5) cognitive assessments, 6) assessments informing placement recommendations, , and 7) assessments informing treatment recommendations.

The service also offers evidence-based treatment with primary focus on violence, sexual offending and personality disorder.

Rational

As a relatively new service, the assessment package offered has grown organically according to the needs of the young people being referred and the growing areas of expertise offered by the expanding team. Each young person is therefore currently offered an individually tailored assessment package that is based upon the referral question and falls within the constraints of team expertise. Assessment packages usually include a review of background information, clinical interview and observation, and a selection of standardised assessment measures including neuropsychological (e.g. WISC-IV) and psychometric tests (e.g. NOVACO), and structured risk assessments (e.g. SAVRY). Currently no standard assessment package (neither a compulsory comprehensive package for all young people referred, nor a compulsory basic package with additional optional components as required by the young person's presentation and/or referral question) is offered.

The advantages of offering individually tailored assessment packages include the retention of difficult to engage young people and the provision of concise reports in a timely and responsive manner by avoiding unnecessarily lengthy assessment. However disadvantages are also present. Young people referred to the service are complex in presentation and frequently characterised by difficulties across multiple domains, including individual risk factors (e.g. neurodevelopmental disorder, emerging personality disorder), family risk factors (e.g. chaotic and socially deprived families, domestic violence), peer group risk factors (e.g. gang affiliation and/or involvement), and community risk factors (e.g. high levels of socio-economic deprivation and crime). Measures used within the individually tailored assessments conducted by the team are therefore likely to differ significantly across client group, dependent on the referral question and the client's presentation. The relative absence of common measures across the client group prevents exploration of client group profiles and therefore limits the ability to ensure the team is able to meet the needs of the client group, for example in terms of providing relevant expertise and or evidence based assessment.

The relative absence of common measures across the client group also makes it difficult to ascertain whether assessments offered are compliant with current national governance targets, for example the need to standardise screening of substance use in young people as defined by the Practice Standards for young people with substance misuse problems (CCQI, 2012).

Aims

The aim of this service evaluation project is to:

- (1) PART I a - Audit the current assessment process of the National and Specialist Child and Adolescent Forensic Psychology Service, in order to
- (2) PART I b - Establish compliance with national governance, and
- (3) PART II - Establish the level of referrer satisfaction.

Where non-compliance, inconsistency and or referrer dissatisfaction is evident, a further aim is to:

- (4) Make recommendations for the improvement of the current assessment process by developing either a compulsory comprehensive or a compulsory basic assessment package, to ensure the service is providing the most effective and appropriate assessment for their client group.

PART I a: An audit of the service's current assessment process

Prior to establishing service compliance with national governance targets, the current assessment process of the National and Specialist Child and Adolescent Forensic Psychology Service was examined.

METHOD

Design

Referrals for assessment received by the service were examined through a review of the service's existing referral database. Referrals for assessment that had been accepted and completed up to December 2012 were identified and included in the audit.

Permission to complete this service audit was given by the King's College Hospital NHS Foundation Trust (see Appendix 1).

Procedure

Reports of all completed referrals for assessment (up to December 2012) were examined manually by the author. Data related to the assessment process was identified and recorded on a secure, electronic database. Where questions relating to the assessment process arose, the relevant professionals in the service were consulted.

RESULTS

Demographics

By December 2012, a total of 18 referrals for assessment had been accepted and completed by the service. The young people who had been referred to the service were between the ages of 13 and 20 years, with a mean age of 17 years. Sixteen of the young people referred were male and two were female. The referral source varied; nine referrals were from CAMHS services (four from local Tier 3 CAMHS services and five from National and Specialist Tier 4 CAMHS services), seven from Solicitors, one from a YOT, and one from Social Services.

Reasons for referral

At the time of this evaluation, the reasons for referral to the service varied and referrals could include requests for multiple types of assessments. A total of 12 forensic risk assessments, 12 offence related assessments (i.e. assessment to determine whether a mental health difficulty or cognitive inability have contributed to the young person committing an offence), seven Court related assessments (i.e. assessment of the young person's ability to understand and participate in the trial process), four diagnostic mental health assessments, seven cognitive assessments, three assessments informing placement recommendations, and nine assessments informing treatment recommendations were requested and completed by the service for the 18 young people referred (see Figure 1 below).

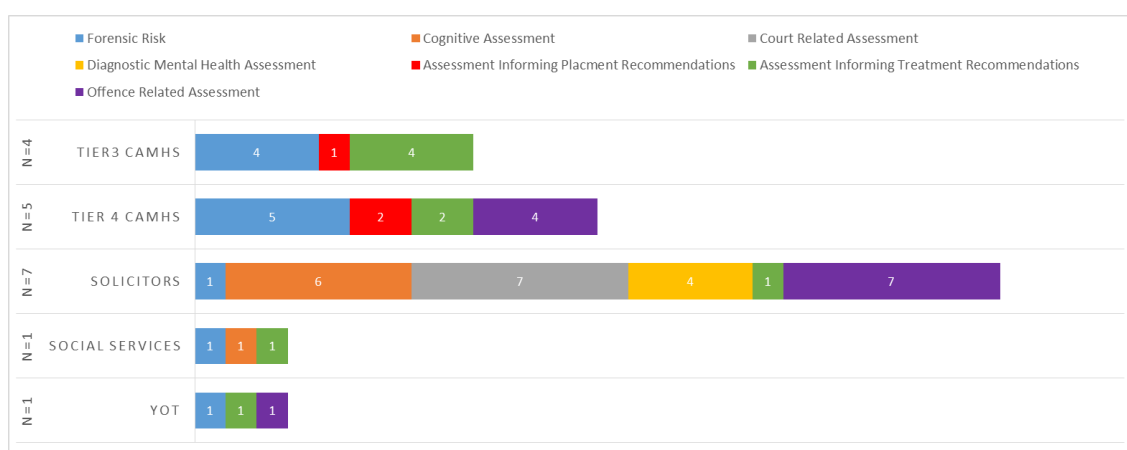


Figure 1 Assessment requests received and completed by the service.

Assessment parts

All assessments conducted by the service included a review of the background information, clinical interviews, and informal observation of the young person during the assessment (except where access to the client or background information was denied), and all assessments were completed collaboratively by two or more professionals from the service. Where specifically requested and/or relevant to the referral reason (i.e. for diagnostic mental health assessments), the assessment conducted by the service additionally included formal observation of the young person in school and/or at home.

Of the 18 assessments completed at the time of the evaluation, all included a review of background information. 17 out of the 18 assessments included a clinical interview with the young person and a clinical interview with their primary caregiver. The only case for which clinical interviews were not completed was due to the service being prevented access to the young person and their family. For this case findings were based solely on review of the background information.

For the 17 assessments that included a clinical interview with the young person and their primary caregiver, additional informant interviews were conducted in four cases. Collateral interviews included other family members (2/18; i.e. siblings), social workers (1/18), placement managers (3/18), YOT officers (2/18), and others (3/18; i.e. a key worker or teacher).

Further, for the 17 assessments that included a clinical interview with the young person and their primary caregiver, additional formal observation of the young person was conducted in three cases. One young person was observed at home and in School, and two young people were observed at home (see Figure 2 below).

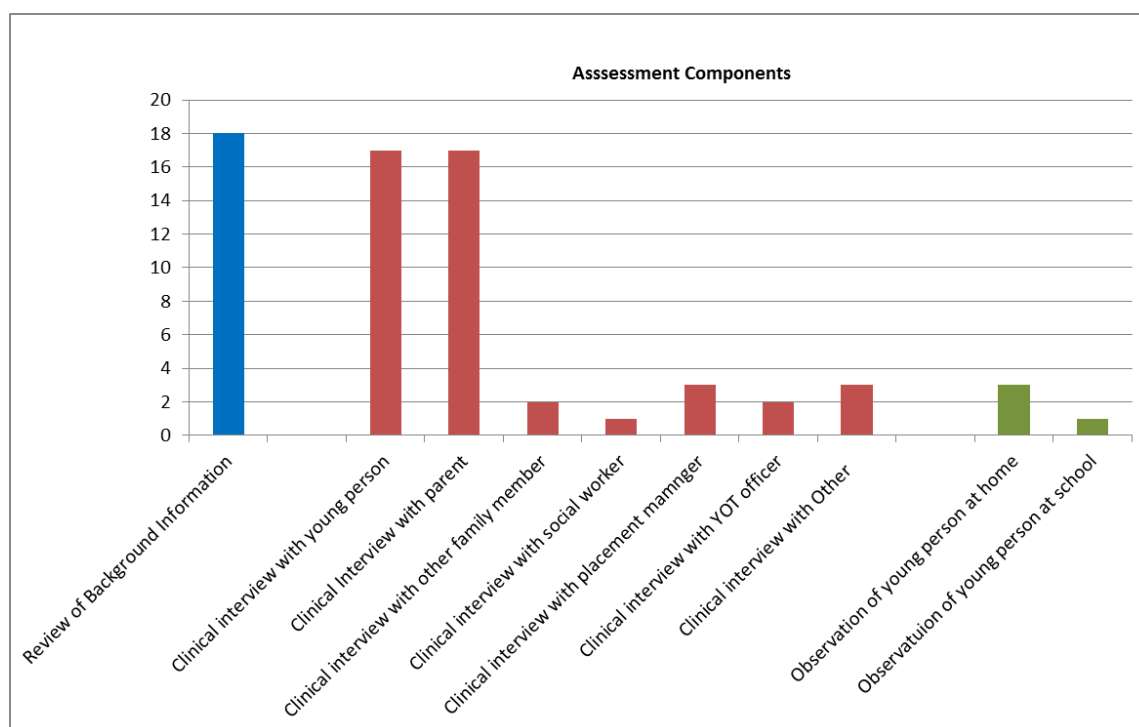


Figure 2 Assessment parts of completed assessments by the service.

Assessment domains and measures

Table 1 illustrates the domains that were addressed in the review of background information, the clinical interview with the parent(s)/carer(s)/other(s), and the clinical interview with the young person (except where these were not relevant to the referral).

Where specifically requested or relevant to the referral, the assessments completed by the service also included a selection of standardized measures (see Appendix 2 for a list of all standardized measures that were used during the assessment of the 18 young people referred).

For the 18 assessments completed at the time of the evaluation, 15 standardized tests of general intellectual skills, 13 structured risk assessment measures, 11 diagnostic mental health measures, five behavioural measures, five measures of anger, five measures of depression or anxiety, four measures of legal concern and one other measure were employed by the service (see Figure 3 below).

Table 1 Domains addressed in the service's current assessment process

<i>Domain</i>	<i>Background Information</i>	<i>Interview with parent(s)/ carer(s)/ other(s)</i>	<i>Interview with young person</i>
<i>Family History & Functioning</i>	X	X	
<i>Personal History</i>	X		
<i>Developmental History</i>	X		
<i>Medical History</i>	X		
<i>Psychiatric History</i>	X		
<i>Educational History & Academic Functioning</i>	X	X	
<i>Forensic History</i>	X		
<i>Alcohol and Drug use</i>	X	X	X
<i>Access & use of weapons</i>	X		
<i>Previous Assessment & Intervention</i>	X		
<i>Understanding of the Referral & Presenting Concerns</i>		X	X
<i>Social Functioning</i>		X	X
<i>Anger Management Difficulties</i>		X	X
<i>Future Intervention Plan</i>		X	X
<i>Emotional Functioning</i>			X
<i>Peer Group</i>			X
<i>Suicidality</i>			X
<i>Observation</i>			X

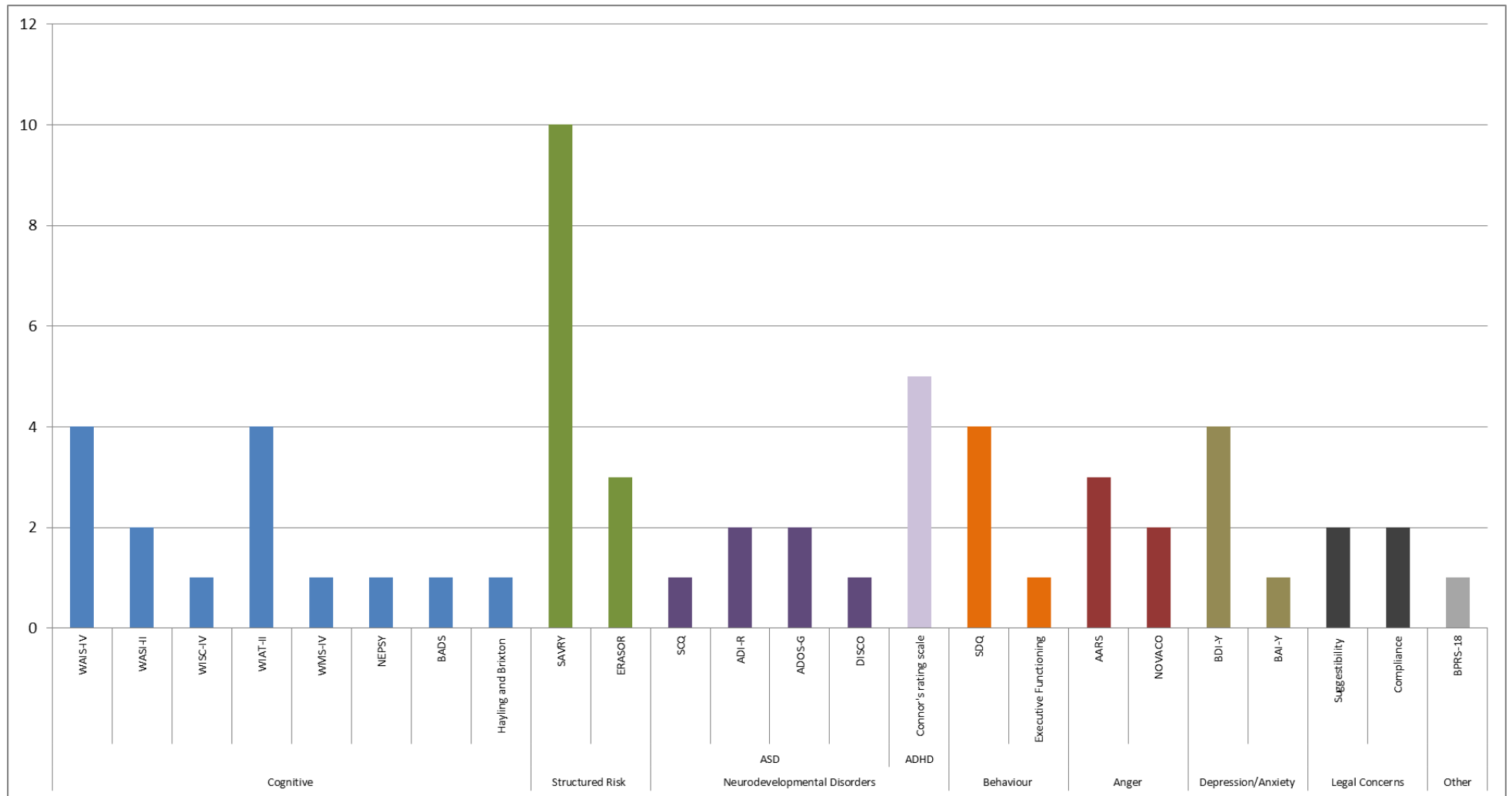


Figure 3 Number and kind of standardized assessment measures employed by the service

PART I b: Compliance with national governance targets

The second aim of this project was to establish service compliance with national governance targets.

METHOD

Design

National guidelines published between 2005 and 2015 that were relevant to the client population (i.e. those guidelines meeting inclusion criteria as defined below) were identified and examined. No systematic search was employed. National guidelines were identified primarily through (1) The British Psychological Society (BPS), (2) the Department of Health (DoH), (3) the Royal College of Psychiatry and specifically its two sub-sections – the Forensic College Centre for Quality Improvement and the Quality Network for Forensic Mental Health Services, and (4) the National Institute for Health and Clinical Excellence (NICE).

Procedure

The relevant guidelines were examined manually by the author and assessment process related data was identified and recorded. Guidelines were included if they i) addressed the child and adolescent population (i.e. ages between 8-18 years); ii) addressed the forensic population (i.e. those who have committed or present with significant risk of serious violence, fire-setting or sexually harmful behaviour); iii) addressed mental health problems relevant to the child and adolescent forensic population (i.e. conduct disorder, ADHD, antisocial or borderline personality disorder, PTSD, depression, psychosis, self-harm, ASD, and substance misuse); iv) addressed psychosocial difficulties relevant to the child and adolescent forensic population (i.e. being looked after, maltreatment, belonging to a gang); and v) included assessment process relevant information (i.e. either recommendation of specific quantitative assessment tools such questionnaires or tests, or recommendation of qualitative assessment domains).

RESULTS

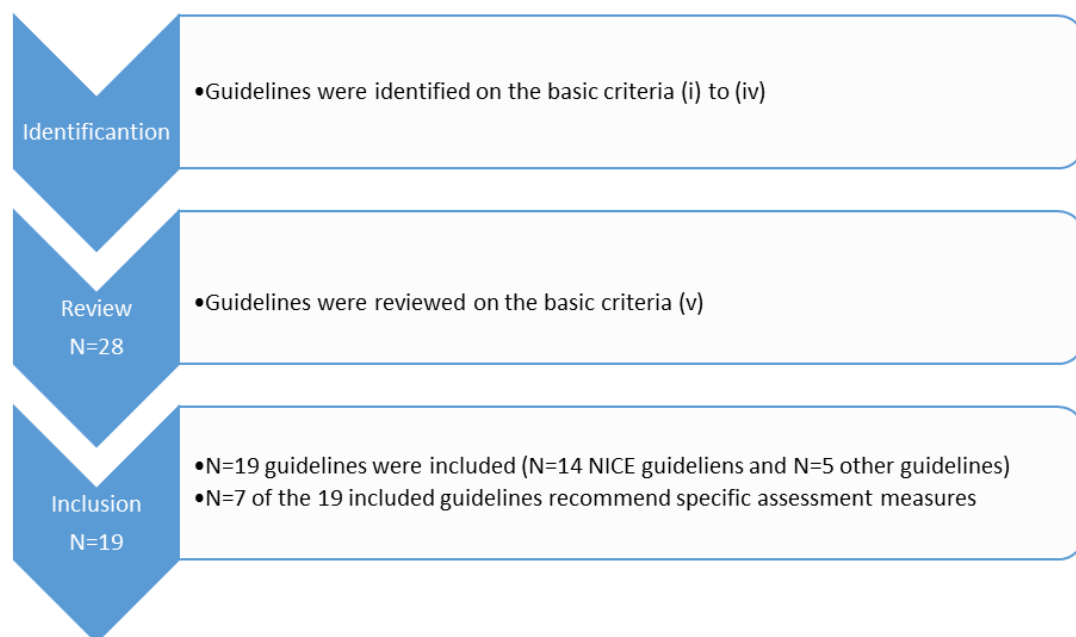


Figure 4 Review of national governance targets.

Figure 4 presents an illustrative summary of the identification and review process. Following identification and review, a total of 19 relevant guidelines were included in the review of this section. Seven of these give recommendation on specific assessment tools (i.e. questionnaires and/or tests) rather than or in addition to general advice regarding the assessment process. A brief summary of each guideline is provided in Appendix 3.

Table 2 shows the assessment parts that are recommended by the guidelines reviewed herein. The recommendation totals for each assessment part were calculated in percentages. Where an assessment part is recommended by more than 50% of all guidelines reviewed herein, this part was considered to be *required* (indicated in red colour). Where an assessment part is recommended by less than 50% of all guidelines reviewed herein, this part was considered to be *desirable* (indicated in orange colour). The same approach was used to identify *required* and *desirable* assessment domains and measures. Table 3, Table 4 and Table 5 provide an overview of all assessment domains and measures that are recommended by the guidelines reviewed herein, as well as recommendation totals (in percentages).

Table 2 Required and desirable assessment parts (as recommended by national guidelines)

Guideline	Assessment Parts									
	Background Information	Liaison with other services/professionals	Clinical Interview with young person	Clinical Interview with parent(s)/carer(s)/other(s)	Observations				Feedback session	
					At assessment	In School/College	At home	With peers	With referrer	With young person and or parent(s)...
FCAMHS: a map of current national provision and a proposed service model for the future	X	X	X		x					
The Forensic Mental Health Matrix	X	X	X		X					
The Health needs assessment of young people in London.	X	X	X	X	X					
Practice standards for young people with substance misuse problems	X	X	X	X	X					
The Quality Network for Community CAMHS Service Standards	X	X	X	X	X				X	X
NICE clinical guidelines 26			X	X	X					
NICE clinical guidelines 28			X	X	X	X	X	X		
NICE clinical guidelines 51	X		X		X					
NICE clinical practice guidelines 52	X		X		X					
NICE clinical guidelines 72	X	X	X	X	X					
NICE clinical guidelines 77			X		X					
NICE clinical guidelines 78			X		X					
NICE clinical guidelines 115			X		X					
NICE clinical guidelines 120	X	X	X	X	X					
NICE clinical guidelines 128	X	X	X	X	X	X	X	X		
NICE clinical guidelines 133			X		X					
NICE clinical guidelines 155	X	X	X	X	X					
Psychosis and schizophrenia in children and young people. NICE guidelines on recognition and management	X	X	X	X	X					
NICE clinical guidelines 158	X		X	X	X	X	X	X		
Recommendation total	68%	53%	100%	58%	100%	16%	16%	16%	5%	5%

Required **Desirable**

Table 3 Required and desirable assessment domains (as recommended by national guidelines)

Guideline	Assessment Domains										
	Psychiatric		Psychological & Psychosocial				Social				
	Mental Health	Alcohol & Substance Misuse	Cognitive Functioning	Forensic History & Risk	Family Functioning & Parenting	History of Trauma, Bullying & Discrimination	Social Networks & relationships	Accommodation	Culture & Ethnicity	Carer Responsibilities & Safeguarding	Exercise & Leisure Activities
FCAMHS: a map of current national provision and a proposed service model for the future	X			X							
The Forensic Mental Health Matrix	X			X							
The Health needs assessment of young people in London.	X			X	X					X	X
Practice standards for young people with substance misuse problems	X	X		X	X	X	X	X	X	X	X
The Quality Network for Community CAMHS Service Standards	X	X	X	X	X		X		X		
NICE clinical guidelines 26	X			X	X	X	X		X		X
NICE clinical guidelines 28	X	X		X	X	X	X	X	X	X	X
NICE clinical guidelines 51	X	X					X	X	X	X	X
NICE clinical practice guidelines 52		X									
NICE clinical guidelines 72	X				X		X	X	X	X	X
NICE clinical guidelines 77	X	X									
NICE clinical guidelines 78	X	X									
NICE clinical guidelines 115		X	X								
NICE clinical guidelines 120	X	X		X	X	X	X	X	X	X	X
NICE clinical guidelines 128	X		X	X	X	X	X	X	X	X	X
NICE clinical guidelines 133			X								
NICE clinical guidelines 155	X	X		X	X	X	X	X	X	X	X
Psychosis and schizophrenia in children and young people. NICE guidelines on recognition and management	X	X	X	X	X	X					
NICE clinical guidelines 158	X	X			X		X	X		X	
Recommendation total	84%	63%	26%	58%	58%	37%	53%	42%	47%	47%	47%

Required **Desirable**

Table 4 Required and desirable assessment domains continued (as recommended by national guidelines)

Guideline	Assessment Domains				Needs & Strengths (including Goals)
	Developmental	Education or Occupational			
	Social, Cognitive & Motor Development	Attendance at School/College	Educational Attainment	Employment or Functional Activity	
FCAMHS: a map of current national provision and a proposed service model for the future					
The Forensic Mental Health Matrix					X
The Health needs assessment of young people in London.					X
Practice standards for young people with substance misuse problems	X	X	X	X	X
The Quality Network for Community CAMHS Service Standards					X
NICE clinical guidelines 26					X
NICE clinical guidelines 28		X	X	X	X
NICE clinical guidelines 51		X	X	X	X
NICE clinical practice guidelines 52					
NICE clinical guidelines 72	X	X	X	X	X
NICE clinical guidelines 77					
NICE clinical guidelines 78		X	X	X	X
NICE clinical guidelines 115					
NICE clinical guidelines 120		X	X	X	X
NICE clinical guidelines 128	X	X	X	X	X
NICE clinical guidelines 133					X
NICE clinical guidelines 155	X	X	X	X	X
Psychosis and schizophrenia in children and young people. NICE guidelines on recognition and management	X				X
NICE clinical guidelines 158	X	X	X	X	
Recommendation total	32%	47%	47%	47%	74%

Required **Desirable**

Table 5 Required and desirable assessment measures (as recommended by national guidelines)

Guideline	Specific Assessment Measure			
FCAMHS: a map of current national provision and a proposed service model for the future	SDQ; CHL; ESQ; CGAS; HoNOSCA; GBO			
Practice standards for young people with substance misuse problems	AUDIT-C; SADQ; CRAFFT; SCIFA; MASQ			
NICE clinical guidelines 28	MFQ; HoNOSCA; SDQ			
NICE clinical guidelines 72	Conner's; CGAS; SDQ			
NICE clinical guidelines 77	PCL-R:YV; SAVRY; ERASOR			
NICE clinical guidelines 115	AUDIT-C; SADQ; LDQ; CIWA-Ar; APQ; MMSE; ADI; TASI			
NICE clinical guidelines 158	SDQ			
Recommendation total	SDQ 57%	HoNOSCA 29%	CGAS 29%	AUDIT-C 29%

Required	Desirable
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Establishing Service Compliance

The Care Quality Commission (CQC) Judgement framework (CQC, 2012) was used to establish service compliance with national guidelines (i.e. recommended required and desirable assessment components). These guidelines describe that where a service complies with required national targets 80% to 100%, the service is considered to be compliant. Where a service complies with required national targets less than 80%, the service is considered to be non-compliant and the impact of this on people who use the service should be assessed and judged to be either: (1) minor – people who use the service experienced poor care that had an impact on their health, safety or welfare OR there was a risk of this happening. The impact was not significant and the matter could be managed or resolved quickly; (2) moderate – people who use the service experienced poor care that had significant impact on their health, safety or welfare OR there was a risk of this happening. The matter may need to be resolved quickly; or (3) major – people who use the service experienced poor care that had a serious current or long-term impact on their health, safety and welfare OR there was a risk of this happening. The matter needs to be resolved quickly. For the purpose of this

evaluation, compliance percentages were set based on the CQC Judgement framework (CQC, 2012; see Table 6 below).

Table 6 Compliance percentages

Compliance rating	Level of service compliance and impact on service users
Compliant	80-100% service compliance
Non-compliant with minor concern	60-79%, and /or People who use the service experienced poor care that had an impact on their health, safety or welfare OR there was a risk of this happening. The impact was not significant and the matter could be managed or resolved quickly.
Non-compliant with moderate concern	40-59%, and /or People who use the service experienced poor care that had significant impact on their health, safety or welfare OR there was a risk of this happening. The matter may need to be resolved quickly.
Non-compliance with major concern	Less than 40%, and /or People who use the service experienced poor care that had a serious current or long-term impact on their health, safety and welfare OR there was a risk of this happening. The matter needs to be resolved quickly.
Undetermined	Insufficient evidence to establish service compliance

Service compliance (in percentages) was calculated on the basis of the results from the audit in PART I a of this evaluation. Where no or not enough evidence was available from the results of the audit in Part I a, service compliance was rated as undetermined. Service compliance with recommended *required* and *desirable* assessment parts, domains and measures is presented and discussed below.

Service compliance with *required* and *desirable* Assessment Parts

The audit of national guidelines identified five assessment parts as *required*: (1) review of background information; (2) liaison with other services and or professionals; (3) clinical interview with the young person; (4) clinical interview with parent(s), carer(s) and or other(s); and (5) observation of the young person at assessment (i.e. informal). The results from PART I a of this evaluation indicate that (at the time of evaluation) the National and Specialist Child and Adolescent Forensic Psychology Service is compliant in four of these five areas (see Table 7 below).

Table 7 Service Compliance with required Assessment Parts (as recommended by National guidelines)

Assessment Part		Level of service compliance (%) and impact on service users	Compliance Rating
Review of background information		100%	Compliant
Liaison with other services/professionals		50%	Undetermined
Clinical Interview with young person		94%	Compliant
Clinical Interview with informant		100%	Compliant
Observation	At assessment (i.e. informal)	94%	Compliant

As outlined in Table 7, background information was reviewed for all of the 18 young people who had been referred for assessment (100%). A clinical interview was conducted with 17 of these 18 young people (94%), and a clinical interview with an informant (parent, carer and or other) was conducted for all 18 young people (100%). Informal unstructured observation of the young person at assessment was also completed for 17 of the 18 young people referred (94%). There was therefore compliance across all four *required* areas.

In contrast, liaison with other services and or professionals was completed for only nine of the 18 young people referred (50%). While this indicates ‘non-compliance with moderate concern’ on the basis of frequency of completion, it is important to note that evidence for liaison work by the service was taken from reports that specifically mentioned clinical interview with other professionals. As such, there might not have been enough evidence to accurately measure service compliance in this area (CQC, 2014) and a compliance rating could therefore not be established.

In addition to the *required* assessment parts, the following five assessment parts were identified as *desirable* by the audit of national guidelines: (1) observation of the young person in school; (2) observation of the young person at home; (3) observation of the young person with peers; (4) a feedback session with the referrer; and (5) a feedback session with the young person and or parents(s) or carer(s). The results from PART I a of this evaluation indicate that (at the time of evaluation) service compliance could not be established in all five of these areas (see Table 8 below).

Table 8 Service compliance with the desirable Assessment Parts (as recommended by National guidelines)

Assessment Part		Level of service compliance (%) and impact on service users	Compliance Rating
Formal structured Observation	In School	5%	Undetermined
	At home	17%	Undetermined
	With peers	5%	Undetermined
Feedback session	With referrer	0%	Undetermined
	With young person and/or primary caregiver	0%	Undetermined

As outlined in Table 8, formal structured observation at School was completed for only one of the 18 young people referred for assessment (5%). A formal structured observation at home was completed for three of the 18 young people (16%), whilst a formal structured observation with peers was again only completed for one of the 18 young people (5%). No feedback session with either the referrer, or the young person and their primary caregiver was held by the service for any of the 18 young people referred for assessment (0%).

While these percentages would indicate ‘non-compliance with major concern’, it is important to note that it was not possible to ascertain from the assessment reports whether attempts had been made to observe the young person in different settings but denied, or whether feedback sessions were offered but declined. As such, there might not have been enough evidence to accurately measure service compliance in these areas (CQC, 2014) and a compliance rating could therefore not be established.

Service compliance with *required* and *desirable* Assessment Domains

Within the assessment process, several assessment domains can be addressed through (1) the review of background information and clinical interviews and/or (2) the use of specific testing or measures (e.g. structured risk assessment measures; see Figure 3 in PART 1 a). For the purpose of this evaluation, ‘compliance’ with a *required* assessment domain was therefore defined as the service addressing this domain through BOTH (1) the review of background information and clinical interviews AND (2) the use of

specific testing or measures. Where the service was found to be 'non-compliant' through one or both of these areas, the lower 'Level of Service Compliance' percentage frequency rating was used as overall service 'Compliance Rating' with this *required* assessment domain.

In contrast, 'compliance' with a *desirable* assessment domain was defined for the purpose of this evaluation as the service addressing this domain through EITHER (1) the review of background information and clinical interviews OR (2) the use of specific testing or measures. Where the service was found to be 'compliant' through one or both of these areas, the higher 'Level of Service Compliance' percentage rating was used to guide the overall service 'Compliance Rating' with this *desirable* assessment domain.

The audit of national guidelines identified a total of six assessment domains, of which four had further sub-domains. Of these, one domain and five sub-domains were identified as *required*: (1) Psychiatric – mental health; (2) Psychiatric – alcohol and substance misuse; (3) Psychological & Psychosocial – forensic history and risk (to self and others); (4) Psychological & Psychosocial – family functioning and parenting; (5) Social – social networks and relationships; and (6) Needs & Strengths. The results from PART I a of this evaluation indicate that (at the time of evaluation) the National and Specialist Child and Adolescent Forensic Psychology service is compliant in one of these areas only (see Table 9 below).

Table 9 Service compliance with the required Assessment Domains (as recommended by National guidelines)

Assessment Domain	Level of service compliance (%) and impact on service users	Compliance Rating
Psychiatric – mental health	100% through review of background information and clinical interviews	Non-compliance with major concern
	28% through the use of specific testing/measures	
Psychiatric – alcohol and substance misuse	100% through review of background information and clinical interviews	Non-compliance with major concern
	0% through the use of specific testing/measures	
Psychological & Psychosocial – forensic history and risk	100% through review of background information and clinical interviews	Non-compliant with minor concern
	67% through the use of specific testing/measures	
Psychological & Psychosocial – family functioning and parenting	100% through review of background information and clinical interviews	Non-compliance with major concern
	0% through the use of specific testing/measures	
Social – social networks and relationships	100% through review of background information and clinical interviews	Non-compliance with major concern
	0% through the use of specific testing/measures	
Needs & Strengths	100%	Compliant
	Specific testing or measures are not applicable	

As outlined in Table 9, the service addressed ‘Needs and Strengths’ for all of the 18 young people (100%) that had been referred for assessment through the review of background information and/or within clinical interviews with the young person and their primary caregiver (i.e. within ‘Future Intervention Plan’; see Table 1). Thus evidencing service compliance in this *required* domain.

While results from PART I a also indicate that the service is compliant in the remaining five *required* sub-domains through systematic investigation of all of these areas via the review of background information and or clinical interviews (i.e. 100% of the time; see Table 1), no or insufficient specific testing or measurement was used by the service to investigate these areas. For the assessment sub-domain ‘Social – social networks and relationships’, for example, the service did not employ any specific measure (such as the Multidimensional Scale of Perceived Social Support; MSPSS; Zimet et al, 1998) to investigate social support and relationships within the assessment process. Although the MSPSS is not recommended by the National guidelines reviewed herein, this is a well-established measure of perceived social support that is known to the author and

that has shown good reliability and validity in clinical and non-clinical samples (Zimet et al, 1998). Similarly, for the assessment sub-domain 'Psychological & Psychosocial – family functioning and parenting' the service did not employ a specific measure (such as the parenting scale; PS; Arnold et al, 1993) to investigate parenting style, nor did the service employ a specific measure to investigate alcohol and substance misuse difficulties (such as the Alcohol Use Disorders Identification Test Consumption (AUDIT-C; Bradley et al, 2007) or the CRAFFT Screening tool (Knight et al, 2002)). Again, although the PS is not recommended by the National guidelines reviewed herein, this measure has shown good reliability and validity in clinical and non-clinical samples (Arnold et al, 1993). Finally, for the assessment sub-domains 'Psychiatric – mental health' and 'Psychological & Psychosocial – forensic history and risk' the service did employ specific measures (i.e. the BDI-Y or the BAI-Y, and the SAVRY or ERASOR; see Figure 3). However, the BDI-Y and the BAI-Y were used for only five out of the 18 young people who had been referred for assessment (i.e. 28% of the time), and the SAVRY and the ERASOR were used for only 13 out of the 18 young people who had been referred for assessment (i.e. 67% of the time). The use of no or insufficient specific testing or measurement thus evidences 'non-compliance with major concern' in four *required* areas and 'non-compliance with minor concern' in one *required* area.

In addition to the *required* assessment domains, one assessment domains and nine sub-domains were identified as *desirable* by the audit of national guidelines: (1) Psychological & Psychosocial – Cognitive functioning; (2) Psychological & Psychosocial – History of trauma, bullying and discrimination; (3) Social – Accommodation; (4) Social – Culture and Ethnicity; (5) Social - Carer responsibilities and safeguarding; (6) Social – Exercise & Leisure activities; (7) Developmental; (8) Educational or Occupational – Attendance at School; (9) Educational or Occupational – Educational attainment; and (10) Educational or Occupational – Employment or functional activities. The results from PART I a of this evaluation indicate that (at the time of evaluation) the National and Specialist Child and Adolescent Forensic Psychology Service is compliant in all ten areas (see Table 10 below).

Table 10 Service compliance with the desirable Assessment Domains (as recommended by national guidelines)

Assessment Domain	Level of service compliance (%) and impact on service users	Compliance Rating
Psychological & Psychosocial – Cognitive functioning	100% through review of background information and clinical interviews	Compliant
	39% through the use of specific testing/measures	
Psychological & Psychosocial – History of trauma, bullying and discrimination	100% through review of background information and clinical interviews	Compliant
	0% through the use of specific testing/measures	
Social – Accommodation	100% through review of background information and clinical interviews	Compliant
	Specific testing or measures are not applicable	
Social – Culture and Ethnicity	100% through review of background information and clinical interviews	Compliant
	Specific testing or measures are not applicable	
Social - Carer responsibilities and safeguarding	100% through review of background information and clinical interviews	Compliant
	Specific testing or measures are not applicable	
Social – Exercise & Leisure activities	100% through review of background information and clinical interviews	Compliant
	Specific testing or measures are not applicable	
Developmental	100% through review of background information and clinical interviews	Compliant
	23% through the through the use of specific testing/measures	
Educational or Occupational – Attendance at School	100% through review of background information and clinical interviews	Compliant
	Specific testing or measures are not applicable	
Educational or Occupational – Educational attainment	100% through review of background information and clinical interviews	Compliant
	Specific testing or measures are not applicable	
Educational or Occupational – Employment or functional activities	100% through review of background information and clinical interviews	Compliant
	Specific testing or measures are not applicable	

As outlined in Table 10, the assessment domains that were identified as *desirable* were addressed through review of background information and or clinical interviews (i.e.

within ‘Personal History’, ‘Developmental History’, ‘Educational History & Academic Functioning’, ‘Social Functioning’, and ‘Emotional Functioning’; see Table 1) for all 18 young people who had been referred for assessment (i.e. 100% of the time). Thus evidencing service compliance with all *desirable* assessment domains.

Service compliance with *required* and *desirable* Assessment Measures

In regard to specific measures, the review of national guidelines identified the SDQ as the only *required* measure; the SDQ was recommended by four out of the seven guidelines that suggested specific assessment measures (57%). The results from PART I a of this evaluation indicate that the National and Specialist Child and Adolescent Forensic Psychology Service (at the time of evaluation) is ‘non-compliant with major concern’ in this area. While the SDQ was used by the service, this was only the case for four of the 18 young people who had been referred for assessment (i.e. 22% of the time; see Figure 3).

Finally, the review of national guidelines identified the following three measures as *desirable*: (1) the CGAS; (2) the HoNOSCA; and (3) the AUDIT-C. The CGAS and the HoNOSCA are both general outcome measures (equivalent to the SDQ), and both are recommended by two out of the seven national guidelines that suggested specific assessment measures (29%). The AUDIT-C is a measure that aids investigation of alcohol and substance misuse in young people, and it was recommended by two out of the seven national guidelines that suggested specific assessment measures (29%). The results from PART I a of this evaluation show that (at the time of evaluation) the National and Specialist Child and Adolescent Forensic Psychology Service was not using any of these measures and is thus ‘non-compliant with major concern’ in the area of *desirable* assessment measures.

CONCLUSION

In conclusion, the results from the audit of the service’s current assessment process (PART I a) together with the review of national governance guidelines (PART I b) show that (at the time of evaluation) the National and Specialist Child and Adolescent Forensic Psychology Service complies with all *required* assessment parts, except for

‘Liaison with other service and professionals’. However, there was not enough evidence to reliably measure compliance in this area. Similarly, not enough evidence was available to establish service compliance with any of the five *desirable* assessment parts.

At the time of evaluation, The National and Specialist Child and Adolescent Forensic Psychology Service also complies with one out of the six *required* assessment domains and/or sub-domains that were identified through the review of national governance guidelines, through the service’s systematic review of background information for cases and completion of clinical interviews during the assessment process. However, for the remaining five *required* assessment sub-domains, the service was found to be ‘non-compliant with major concern’ for four of these, and ‘non-compliant with minor concern’ for the final domain.

Finally, the service was found to be ‘non-compliant with major concern’ in their use of *required* and *desirable* measures that were identified through the review of national governance guidelines. Where non-compliance was identified recommendations for service improvement are suggested in the following.

RECOMMENDATIONS

The children and young people referred to and assessed by the National and Specialist Child and Adolescent Forensic Psychology Service provide a very heterogeneous population with complex presentations and often difficulties across multiple domains. As such, a wide variety of national governance documents were searched and considered for this service evaluation. These were equally heterogeneous in their recommendations of either general assessment domains, or recommendations of specific assessment tools, and the specific assessment tools recommended were often specific to particular mental health problems and/or alcohol or substance misuse.

Nevertheless, the guidelines reviewed herein recommend that the assessment process should include five *required* assessment parts, that address six *required* assessment

domains or sub-domains, and include (at least) one *required* generic outcome measure.

The results of this evaluation found little evidence of the service's liaison work with other services and/or professionals (an assessment part that was identified as *required* through the review of national guidelines herein), which made rating compliance in this area difficult. A recommendation to the service is therefore to provide more detailed and systematic evidence of their liaison work with other services and/or professionals, for example, through a separate section within their assessment reports.

Further to this, the results of this evaluation found the service to be 'non-compliant with major concern' for four of the six assessment domains and/or sub-domains that were identified as required through the review of national guidelines herein. Similarly, the results of this evaluation found the service to be 'non-compliant with minor concern' for one of the six assessment domains and/or sub-domains that were identified as required through the review of national guidelines herein. For all of these five assessment domains or sub-domains 'non-compliance' was a result of the service employing no or unsystematic specific testing or measurement. A second recommendation to the service is therefore to implement the systematic use of measures of mental health (e.g. the BDI-Y and the BAI-Y), alcohol and substance misuse (e.g. the AUDIT-C), family functioning (e.g. the PS), social relationships (e.g. the MSPSS), and structured risk (e.g. the SAVRY or the ERASOR) within the assessment of every child and young person referred to the service for assessment.

Lastly, this evaluation found the service to be 'non-compliant with major concern' in their use of the *required* and *desirable* assessment measures that were identified through the review of national guidelines herein. A third recommendation to the service is therefore to start the systematic use of a generic outcome measure (i.e. the SDQ) with all children and young people who are referred to and assessed by the service.

Finally, due to the heterogeneous population with complex presentations, comorbidities and difficulties across domains, the development of a compulsory *comprehensive* assessment package for all individuals referred to the service was not considered to be appropriate. Therefore, a compulsory *basic* assessment package (including all *required* assessment parts and domains as recommended by the national guidelines reviewed herein, with additional *desirable* and optional components as required by the individual's presentation and or referral question) was developed and is presented in Appendix 4.

PART II: Referrer satisfaction

Finally, this project aimed to establish the level of referrer satisfaction with the service. Qualitative feedback regarding the quality and utility of assessments conducted was therefore obtained from referrers.

METHODS

Design

Referrals for assessment received by the National and Specialist Child and Adolescent Forensic Psychology Service were examined through a review of the service's existing referral database. Referrals for assessment that had been accepted and completed (up to December 2012) were identified. For these referrals qualitative feedback was obtained from referrers through a standard service quality questionnaire (the System Quality and Performance Measure, SQPM), which was adapted to reflect the specific needs of the service (see Appendix IV).

Permission to complete this service evaluation was given by the King's College Hospital NHS Foundation Trust (see Appendix 1).

Procedure

A cover letter and a service specific referrer satisfaction questionnaire (the adapted version of the SQPM) were designed prior to the review of the referral database and circulation to referrers (See Appendix 5 and 6). No patient identifiers (e.g. name, dates of birth etc.) were recorded on either document to ensure anonymity.

The service specific referrer satisfaction questionnaire was divided into four sections:

- (1) Personal details of referrer/referring service – this section was optional,
- (2) Access to the Child and Adolescent Forensic Psychology Service,
- (3) Quality of the Child and Adolescent Forensic Psychology Service, and
- (4) The Working Relationship with the Child and Adolescent Forensic Psychology Service.

Referrers who had referred to the service more than once were asked to complete the questionnaire in relation to their most recent referral. The questionnaire also invited additional comments relating to any aspect of the service. This data was recorded and grouped according to content, to reveal themes to guide service delivery and development.

The service specific referral satisfaction questionnaire was initially circulated to all team members for approval, and updated to incorporate further items and suggestions. The questionnaire was then mailed out to all referrers accompanied by the cover letter and a return envelope. In order to maximize the response rate, questionnaires, cover letters and return envelopes were also sent to key care coordinators and significant other professionals involved in the young person's care where this was appropriate (e.g. professionals who might have been involved in the initial referral and/or who would have received a copy of the assessment report). To ensure confidentiality, each referrer, key care coordinator and significant other professional was assigned an identification number, and all information was analyzed anonymously. A reminder and clarification phone call was delivered to all referrers, key care coordinators and significant other professionals after approximately two weeks. A second reminder phone call was delivered to all non-responders after an additional two weeks. Responses that had been received back by March 2013 were included in the analysis.

RESULTS

A total of 18 referrals for assessment had been accepted and completed by the National and Specialist Child and Adolescent Forensic Psychology Service by December 2012. For these, a total of 26 questionnaires were sent out to main referrers, key care coordinators, and significant other professionals involved in the young person's care. By March 2013, a total of eight questionnaires were received back, providing a response rate of 31%. However, no double responses were received back (i.e. for each young person either the referrer, key care coordinator or a significant other professional responded), providing an actual response rate of 44%. A total of seven

main referrers and one key care coordinator responded. For the purpose of consistency, the results reported below follow the structure of the questionnaire.

(1) Personal details:

Seven out of the eight responders were happy to reveal their personal and service details. Four responses came from CAMHS services, two responses came from Solicitors, one response came from a YOT, and one response was anonymous.

(2) Access to the Service:

This section of the questionnaire asked about the frequency of referrals to the service, the frequency of contact with professionals from the service, the most frequently used means of communication to contact professionals from the service, and the ease of access to professionals from the service.

Results of the questionnaire revealed that at the time of the evaluation, one responder had referred frequently to the service, five responders had referred occasionally, and two responders had referred only once. In addition to this, half of all responders reported frequent contact with professional from the service, and the other half occasional contact. The most frequent means of communication with the service was reported as via phone by six responders, followed by email reported by two responders. Half of all responders felt that it was very easy to access professionals from the service, and the other half felt it was easy.

(3) Quality of the Service:

This section of the questionnaire asked responders to rate their satisfaction with the initial information provided by the service, the referral procedure to the service, the assessment waiting time (i.e. the time between the referral and the individual being seen), the report waiting time (i.e. the time between the individual being seen and a report being provided by the service), and the report the referrers received from the service.

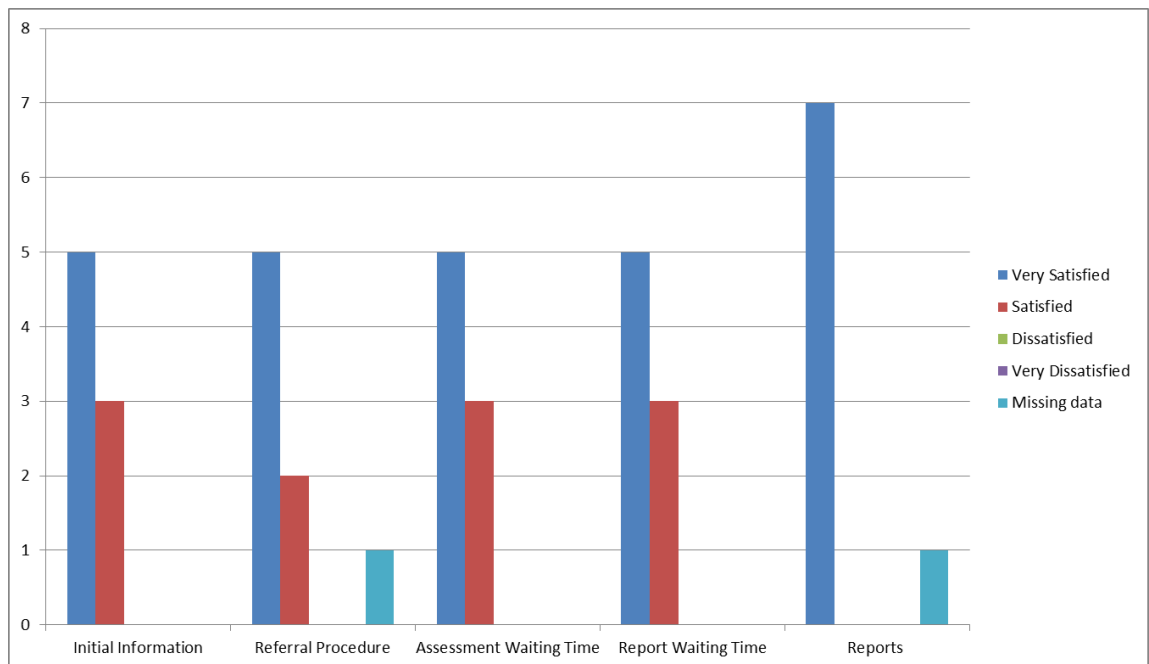


Figure 5 Reported responses on the quality of service received

Results revealed that the majority of referrers were very satisfied with the quality of the service provided (see Figure 5 above). Data was missing at random (i.e. not by the same person).

This section of the questionnaire additionally asked referrers to indicate whether they had received any additional type of feedback (other than the report) and how useful this had been. Half of all responders reported having received additional verbal feedback, and all reported this as very useful.

This section of the questionnaire further inquired about the main and any additional reasons for the referral to the service, the type of assessment that was provided by the service, and how well referrers felt the assessment provided by the service addressed their referral question. Lastly, the section asked referrers to rate whether they felt the input of the service had been beneficial to the individual they referred and whether referrers would refer to the service again.

Results showed that half of all responders had referred primarily for a forensic risk assessment. Of the remaining main reasons for referral, three responders reported that they had referred for a cognitive assessment and there was one referral

requesting a psychology assessment specific for court proceedings. Additional reasons for referral to the service varied, and at the time of the evaluation a total of five forensic risk assessments, seven cognitive assessments, five assessments informing treatment recommendations, and one other type of assessment were provided for the eight individuals referred (see Figure 6 below).

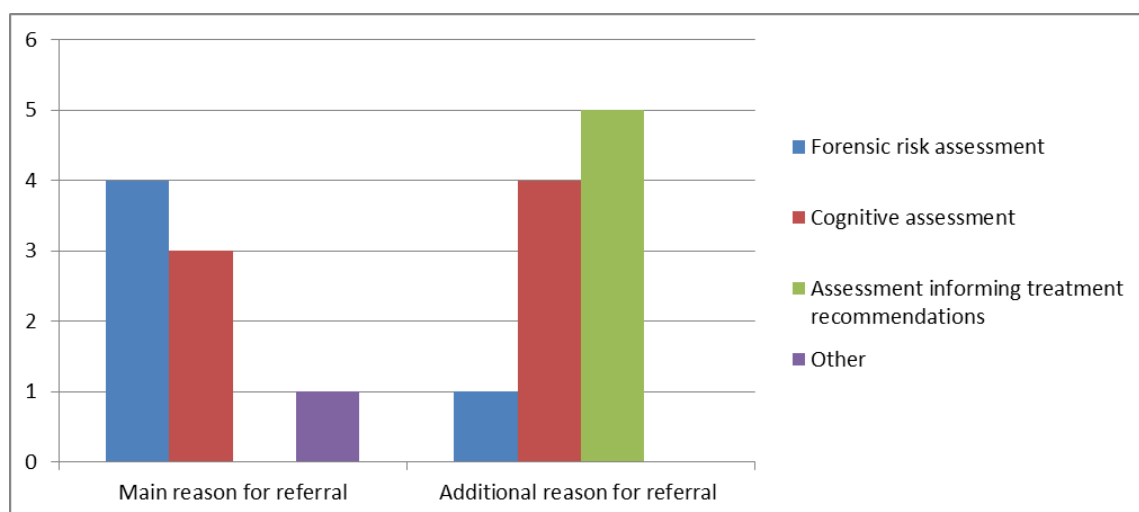


Figure 6 Reported reasons for referral to and assessments provided by the service

Results further revealed that all responders felt that the assessment that was provided by the service addressed the referral question either very well (six out of eight reported responses) or well (two out of eight reported responses), and that the service input was beneficial to the individual they had referred (five responders reporting definitely, and three responders rating probably beneficial). Lastly, seven out of the eight responders said that they would definitely refer to the service again, while one responder reported to probably referring again.

(4) The Working Relationship with the Service:

This section of the questionnaire asked referrers how well supported they felt by the service, how well they felt the service met the needs of the individuals they referred, and how useful the service had been in enabling referrers to become more knowledgeable about emotional and behavioral problems of young individuals at risk of offending.

Half of all responders reported feeling very well supported by the service, and a further three reported feeling well supported. One person did not respond to this question. Similarly, half of all responders reported feeling that the service met the needs of the individual they referred very well, with the other half reporting they felt the service met their needs well. Lastly, the majority of responders (six out of the eight responders) reported feeling the service is very useful in enabling referrers to become more knowledgeable about emotional and behavioral problems of young individuals at risk of offending. Of the remaining two responders, one indicated that the service was 'useful' and the other 'quite useful' in relation to this aim.

(5) Additional comments:

Only three out of the eight responders made additional comments, the majority of which were very positive. One responder commented positively that "reports were proved quickly and in good detail", and highlighted their usefulness in court proceedings. A further responder commented positively on the approachability and helpfulness of the service in supporting the young individual that had been referred. The resourcefulness and thoughtfulness of the service was also positively mentioned, and this responder reported having advised colleagues of "the positive contributions of the service".

There was also one responder who provided additional feedback about referrer's satisfaction with the report provided by the service. Although this responder indicated overall being satisfied with the report, it was mentioned that the wrong test had initially been applied.

CONCLUSION

In conclusion, the results of the referrer satisfaction questionnaire revealed that referrers were overall very satisfied with the service provided by the Child and Adolescent Forensic Psychology Service. Responders reported that the service is easily accessible, provides high quality assessments and reports in a timely manner, is beneficial to both the individuals referred and to the referrer, and that they would refer to the service again. Additional comments further highlighted the

resourcefulness of the service, as well as the detailed and thoughtful approach of its professionals.

RECOMMENDATIONS

The results of the referrer satisfaction questionnaire were presented to and discussed with the service, and the following recommendations were made.

One of the limitations to this part of the evaluation is the low number of responses to the questionnaire. Although the National and Specialist Child and Adolescent Forensic Psychology Service is a relatively new service that at the time of the evaluation had only received and completed a limited number of referrals, other factors may also have contributed to the low response rate. For example, the full contact details of referrers had not been routinely recorded in the service's master referral database. As a consequence, some referrer contact details were sourced manually by the author and may have been incorrect. One recommendation to increase response rate is therefore to routinely record the full contact details of all referrers on the master referrer database, and where possible taking these directly from the referral to ensure accuracy. Furthermore, it was recommended to routinely send out the referrer satisfaction questionnaire with completed reports.

The majority of responders to the referrer satisfaction questionnaire were happy to reveal their contact details and it was therefore possible to examine which referring services had and had not responded and consider possible reasons for this. At the time of the evaluation, the service had received and completed a total of 18 referrals for assessments. Nine of these were made by CAMHS services, including four referrals from Tier 3 CAMHS services and five referrals from Tier 4 CAMHS services. Interestingly, half of the eight responders to the referrer satisfaction questionnaire were from Tier 4 CAMHS services: but no responses were received from Tier 3 CAMHS. The good response rate from Tier 4 CAMHS may reflect their close proximity to the National and Specialist Child and Adolescent Forensic Psychology Service (e.g. located in the same building). This close proximity may support easier and quicker access to and communication with the service, and thus a more effective working relationship.

This may also be reflected in the pattern of referrals for assessment to the service, in which the majority of referrals from CAMHS services were made by teams located in the same Borough as the Child and Adolescent Forensic Psychology Service: with only one referral from Croydon CAMHS and none from (for example) Lewisham CAMHS.

Although this referral distribution may be because the National and specialist Child and Adolescent Forensic Psychology Service is a relatively new service, a further recommendation that arose from this evaluation was to increase communication with potential referring services and to broaden awareness of the service. This recommendation was welcomed during the presentation of the results from the referrer satisfaction questionnaire to the service. It was agreed that updated service leaflets and information sheets were required. These will detail information about what services are offered by the National and Specialist Child and Adolescent Forensic Psychology Service, include quotes on pricing, as well as some of the positive feedback from responders to the referrer satisfaction questionnaire.

One responder to the referrer satisfaction questionnaire reported that the wrong test was administered by the service. During the presentation of the results to the service it was clarified by professionals from the service that this was the result of miscommunication in what the referrer asked for and what the referrer understood this to include. It was noted that different professions can use very different terminology, and that this is particularly prominent between legal and psychology professionals. It was therefore recommended and agreed that clear initial information and quotes of the services offered by the National and Specialist Child and Adolescent Forensic Psychology Service are vital and (as mentioned above) that updated versions of these will be produced and used prior to any service commencing. It was also agreed that a telephone consultation would be held prior to any assessments commencing.

Lastly, the results of the referrer satisfaction questionnaire showed that verbal communication with and feedback from the service was particularly valued. The majority of responders had frequent verbal communication with the service (i.e. via

phone), and all responders who had received additional verbal feedback to their report reported this as very useful. A final recommendation was therefore to increase verbal communication with referring services by possibly offering an initial telephone consultation and by providing routine verbal feedback sessions.

Discussion

Summary of recommendations

On the basis of the results from the audit (PART I a) and evaluation of compliance with national governance targets (PART I b) of this project, a compulsory basic assessment package, including all *required* and *desirable* assessment parts and assessment domains that were identified through the review of national guidelines, with additional optional components was developed (see Appendix 4). The systematic use of a general outcome measure (i.e. the SDQ) was also recommended.

In addition, based on the results of the evaluation of referrer satisfaction (PART III), the following four recommendations were made. These include 1) the routine recording of all referrer details on a master database, and where possible recording these directly from the referral to ensure accuracy; 2) the routine provision of the referrer satisfaction questionnaire with completed reports; 3) the increase of communication with referral sources and advertisement of the service through revised service leaflets and information sheets; and 4) the increase in verbal communication with referral services by offering initial telephone consultations, as well as by the routine provision of (verbal) feedback sessions.

Limitations

There are several limitations that should be considered when interpreting the results of this service evaluation, and specifically the results of Stage I b. Firstly, the limited number of assessments that had been completed by the service at the time of this evaluation makes verification of the systematic use of assessment tools more difficult. As such, it may have been that these questionnaires and tests were used by the service only for the few cases that had been assessed, but this does not imply systematic use. Therefore, future re-evaluation (e.g. in one years' time) will form an important part of ongoing monitoring of compliance.

An additional limitation to this service evaluation is that it did not include an evaluation of service compliance with evidence-based literature. Unfortunately, this

was beyond the scope of this project. A review of the evidence-based literature and an evaluation of service compliance with this is therefore to be recommended, and might comprise a potential future service evaluation project. Although the guidelines reviewed within Stage I b of this project (e.g. the NICE guidelines) include and provide evidence-based recommendations, it could be argued that these are not exclusive and that only certain kinds of research (e.g. large-scale RCTs) reach the threshold for inclusion into these guidelines. Other potentially valuable literature might therefore not have been considered, which given the heterogeneity of the population addressed in this service evaluation, might be particularly relevant and important.

There is also evidence that some outcome/assessment measures are less applicable to forensic populations. For example, in the adult forensic population individuals have been shown to score particularly high on the SDQ, thus leading to a ceiling effect (Fitzpatrick et al, 2010). Accordingly, evaluation of the evidence-based literature should address the validity of outcome/assessment measures in the child and adolescent forensic population.

A review of evidence-based literature and an evaluation of service compliance with this may also provide additional guidance on the use of specific cognitive functioning tests and or structured risk assessment measures. National governance documents do not address these issues, and only advise on assessment parts, domains and specific questionnaires: thereby limiting exploration of client profiles. However, this is a problem common to research and evaluation of this population, which might be improved by the recommended implementation and systematic use of the compulsory basic assessment package with all individuals referred for assessment to the service, and the systematic administration of specific measures (i.e. the optional, *desirable* components of the compulsory basic assessment pack where these are required).

Conclusion

This service evaluation audited the current assessment process of a National and Specialist Child and Adolescent Forensic Psychology Service and established service compliance with national governance targets. At the time of evaluation, the service

complied with all assessment parts that were identified as *required* through the review of national guidelines, except in one area where insufficient evidence prevented a meaningful compliance rating. Service compliance with *required* assessment domains and *required* assessment measures was found to be low, and recommendations for service improvements were made. In addition, a compulsory basic assessment package (with additional, optional components as required by a specific presentation of the individual and/or a specific referral question) for use with all individuals referred to the service was developed. Part of this service evaluation project additionally included the development of a referrer satisfaction questionnaire specific to the National and Specialist Child and Adolescent Forensic Psychology Service. This questionnaire was used to establish level of referrer satisfaction, which was found to be very high for the service. Specific recommendations (such as increase in verbal communication with referral sources) as well as recommendations for future evaluation (such as evaluation of and compliance with evidence-based literature) were made.

Dissemination & Leadership

The results of this service evaluation project were presented to the National and Specialist Child and Adolescent Forensic Psychology Service in stages. Initially, the newly developed referrer satisfaction questionnaire was presented during a team meeting and feedback on its utility was gathered. This feedback was then considered in the finalization of the questionnaire. In a second stage, the results and recommendations of the referrer satisfaction were presented in a further team meeting. Feedback was sought and quotes from responding referrers were provided for future service advertisement. The service has continued to use the referral satisfaction questionnaire and as a result of this evaluation the service has also revised their information leaflets (specifically those for legal professions), and this can be seen as an endorsement of the consultative methods used to involve the team members in the developmental stages. PART II of the service evaluation project also involved the part-supervision of a voluntary assistant psychologist, who was at the time a member of the service. Finally, the results of PART I and the newly developed compulsory assessment package were presented to the service in a third team meeting.

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Appendices

Appendix 1: Ethical Approval

Appendix 4: Audit & Service Evaluation Project Proposal Form (PPF)

Should you require any assistance with completing this proforma, please contact your Local Clinical Audit Project Officer or, for Trustwide audits, the Clinical Audit & Effectiveness Team (details are available on the SLaM Clinical Audit & Effectiveness Internet Site). For local team-based or CAG- wide projects please send your completed PPF to your local Audit Project Manager/Officer, for ethical approval. For Trustwide projects please send your completed PPF to the Corporate Audit Dept. All relevant contact details are on the SLaM Clinical Audit & Effectiveness Team Intranet site.

1(a) Project lead details:	
Name: Rhianna Watts	Job title: Clinical Psychologist
Work Address: Forensic Psychology Service, National and Specialist CAMHS, Michael Rutter Centre, De Crespigny Park, London, SE5 8AZ	
Telephone: 0203 228 2866	Email: Rhianna.Watts@slam.nhs.uk
1(b) Project Title: Audit and development of the assessment process in a new National and Specialist CAMHS service.	
Project start date: November 2012	Project end date: November 2014
1(c) Please tick ✓ one box: Is this project a:	
Clinical Audit (e.g. Measures a standard) <input type="checkbox"/>	A Service Evaluation (e.g. Patient Survey) <input checked="" type="checkbox"/>
1(d) Which CQC Standards does this audit relate to: Please tick ✓ relevant boxes:	
Involvement and Information <input type="checkbox"/>	Personalised Care, Treatment and Support <input checked="" type="checkbox"/>
Safeguarding and Safety <input type="checkbox"/>	Suitability of Staffing <input type="checkbox"/>
Quality Management <input checked="" type="checkbox"/>	Suitability of Management <input type="checkbox"/>
2 (a) Overall project aim or purpose of the audit <p>The Forensic Psychology Service is a new National and Specialist CAMHS assessment and intervention service for young people aged between 10 and 17 years who are engaged in, or present significant risk of, serious violence, fire-setting and/or sexually inappropriate behaviour.</p> <p>Referrals for assessment only, or assessment with a view to treatment if suitable, come from a variety of sources including: mental health professionals within local and national CAMHS teams, Youth Offending Teams, Social Services and Children's Services, Solicitors and the Courts. The reason for referral differs according to the young person's presentation, situation and the referral source; however commonalities exist including requests for a structured forensic risk assessment, a forensic risk formulation, and guidance as to intervention and/or sentencing needs. As a relatively new service, the assessment package offered by the service has grown organically according to the needs of the young people being referred to the service and the growing areas of expertise offered by the expanding team. Each young person is therefore currently offered an individually tailored assessment package that is based upon the referral question and falls within the constraints of team expertise. Assessment packages usually include a review of background information, clinical interview and observation, and a selection of standardised assessment measures including neuropsychological (e.g. WISC-IV) and psychometric (e.g. NOVACO) tests, and structured risk assessments (e.g. SAVRY).</p>	

Currently no standard assessment package (neither a compulsory comprehensive package for all young people referred, nor a compulsory basic package with additional optional components as required by the young person's presentation / referral question) is offered.

The advantages of offering individually tailored assessment packages include the retention of difficult to engage young people and the provision of concise reports in a timely and responsive manner, by avoiding unnecessarily lengthy assessment.

However disadvantages are also present. Young people referred to our service are complex in presentation and frequently characterised by difficulties across multiple domains, including: individual risk factors (*e.g. neurodevelopmental disorder, emerging personality disorder*); family risk factors (*e.g. chaotic and socially deprived families, domestic violence*); peer group risk factors (*e.g. gang affiliation and/or involvement*); and community risk factors (*e.g. high levels of socio-economic deprivation and crime*). Measures used within the individually tailored assessments conducted by our team are therefore likely to differ significantly across our client group, dependent on the referral question and the client's presentation. The relative absence of common measures across the client group prevents exploration of client group profile and therefore limits our ability to ensure the team is able to meet the needs of our client group, for example in terms of providing relevant expertise and/or evidence based treatment. The relative absence of common measures across the client group also makes it difficult to ascertain whether assessments offered are compliant with current national and local governance targets, for example the need to standardise screening of substance use in young people as defined by the recently published Practice Standards for young people with substance misuse problems (CCQI, 2012).

We would therefore like to audit our current assessment process, to establish compliance with national and local governance targets, consistency with evidence-based literature, and the level of referrer satisfaction. Where non-compliance, inconsistency and/or referrer dissatisfaction is evident, we would seek to develop and improve our assessment process. We would also seek to provide relevant standardised components (in addition to the current individually tailored components), to facilitate exploration of the client group and to ensure good coverage of their needs. Upon development of the improved assessment package, we would seek to pilot its use whilst re-auditing compliance with governance targets, consistency with evidence-based literature and level of referrer satisfaction.

2(b) Specific objectives. What are the audit standards or criteria? The definition of a clinical audit is that it compares practice to agreed standards such as those defined in NICE guidelines and clinical policies, protocols and procedures. Please also state the source of your standards or criteria.

At the present time there are no agreed national standards that specifically reference Tier 4 National and Specialist CAMHS for young people with mental health difficulties and offending behaviour. However, the Quality Network for Community CAMHS set out agreed Service Standards in 2011 for community CAMHS teams, with sections 1 (Access and Referral) and 2 (Assessment and Care Planning) having particular relevance for the current audit. In addition, the Care Quality Commission Essential Standards of Quality and Safety sets out agreed standards for all national health services, with outcome 4 (care and welfare of people who use the service) having particular relevance for the current audit. Practice standards for young people with specific mental health difficulties that are frequently found to be comorbid with offending behaviour, for example substance misuse problems (CCQI, 2012), will also be of relevance to the audit.

Given the absence of national standards that specifically reference the work conducted by our team, we would also seek to review evidence-based literature pertaining to adolescents with offending behaviour and comorbid mental health difficulties. This review would seek to establish the epidemiology of our probable client group and guide assessment planning, through identification of 'gold standard' assessment tools and procedures for common mental health difficulties within this population.

Finally, we would also seek to obtain qualitative feedback from referrers regarding the quality and utility of assessments conducted to date. Qualitative feedback shall be obtained from referrers

through a standard service quality questionnaire (the System Quality and Performance Measure, SQPM), which was adapted to reflect our team's work.

By auditing our existing assessment data (routinely recorded within the team's referral and assessment database), we hope to establish compliance with national and local governance standards / targets, consistency with evidence-based literature, and the level of referrer satisfaction. Where non-compliance, inconsistency and/or referrer dissatisfaction is evident, we would seek to develop and improve our assessment process to ensure we are providing the most effective and appropriate assessment for our client group. We would aim to develop a standardised assessment package, with additional optional components as appropriate, that might work towards setting the 'gold standard' for assessment of young people with offending behaviour and mental health difficulties.

2 (c) Does the project relate to an area of Trust Policy? Please check the Policy site on SLAM Intranet.

Yes ☐ No ☒

If Yes, please state which policy _____

2 (d) If the project relates to an area of Trust policy, please confirm that the standards and criteria in the clinical audit have been drawn from standards within the Trust policy?

Yes ☐ No ☐

Comments: N/A

2 (e) Have you submitted your proposed audit data collection tool or questionnaire along with this Project Proposal for approval?

Yes ☒ No ☐

Comments: Appendix 1: Referrer Satisfaction questionnaire

Appendix 2: Cover Letter

2 (f) Does the data collection tool or questionnaire clearly and accurately monitor the standards outlined above?

Yes ☒ No ☐

Comments: _____

2 (g) In which ways do you think the project will improve patient care / outcomes?

The development of common assessment measures across client group will allow us to explore client group profile and therefore enable us to ensure that the needs of our client group are met, by providing relevant expertise and evidence-based treatment.

The development of common assessment measures across the client group will also enable us to ascertain that the assessments offered by our team are compliant with current national and local governance targets. This may also help to develop a *gold standard* assessment package for young people with mental health problems, who have come into contact with forensic services or are at significant risk of offending.

3 (a) Type of project Please Tick ✓ where appropriate – more than one might apply

(A) National	<input type="checkbox"/>	Re-audit	<input type="checkbox"/>	High risk	<input type="checkbox"/>
(B) Trust-wide	<input type="checkbox"/>	Across primary/secondary interface	<input type="checkbox"/>	High volume	<input type="checkbox"/>
(C) Directorate/CAG	<input type="checkbox"/>	Multidisciplinary	<input type="checkbox"/>	Issue of local concern	<input checked="" type="checkbox"/>
(D) Team based	<input checked="" type="checkbox"/>	Uni-disciplinary	<input type="checkbox"/>	Wide variation in practice	<input type="checkbox"/>

Other (please state):

3 (b) Does your project criteria apply to any of the following? If so Please Tick ✓ where appropriate					
NHS Litigation Authority (NHSLA)	<input type="checkbox"/>	Risk Register (high risk)	<input type="checkbox"/>	Complaints	<input type="checkbox"/>
Trust Policy	<input type="checkbox"/>	CQC	<input checked="" type="checkbox"/>	Patient Survey	<input type="checkbox"/>
NICE Guidance	<input checked="" type="checkbox"/>	Business Plan	<input type="checkbox"/>	DOH Policy Implementation Guidance	<input type="checkbox"/>
National Audit	<input type="checkbox"/>	Improving working lives	<input type="checkbox"/>	Issue of local concern	<input checked="" type="checkbox"/>
Any Other (please state)					

4(a) Who will be on the audit steering group? Forensic Psychology Service, including Dr Rhianna Watts, Dr Kate Johnston and Dr Troy Tranah. Clinical Psychologist in Training: Miss Ukwuori-Gisela Kalu. Research Student on Placement with the Forensic Psychology Service: Miss Archana Rameswaran.			
4(b) What consideration has been given to the involvement of patients, carers or the public? <input type="checkbox"/> Full user involvement at all stages of the audit <input checked="" type="checkbox"/> Partial user involvement : auditing referrer satisfaction <input type="checkbox"/> No user involvement (please state why not) _____			
5. Information Governance Requirements: When planning an audit, each project should be evaluated with regard to whether Personal Identifiable Information (PII) needs to be used. Unless there is genuine justification, all PII should be taken out to effectively anonymise the data for audit and research purposes. If you are unsure or need guidance and advice, please contact: dataprotectionoffice@slam.nhs.uk Personal identifiable information (PII) is any piece of information which can potentially be used to uniquely identify, contact, or locate an individual including name, address, full post code, date of birth, gender, ethnicity, NHS number, photographs, videos, audio-tapes etc.			
5(a) Source of data	<input type="checkbox"/> Patient <input type="checkbox"/> Staff <input checked="" type="checkbox"/> Other (please specify) referrer		
5(b) Method of collection	<input checked="" type="checkbox"/> Direct from subjects (questionnaire) <input type="checkbox"/> From an information system (e.g. ePJS) <input checked="" type="checkbox"/> Other Manual review of team referral and assessment database		
5(c) Will the data be fully anonymised?	X Yes		<input type="checkbox"/> No
	If yes, how: Through a coding system (numerical ID). All data collected will be anonymised through participant coding and published only in a collective form: thereby preventing the identification of any individuals who have participated in the research.		If no, why not:
			If no, which personal identifiers will be used
			If no, have you made arrangements to gain consent from data subjects? <input type="checkbox"/> Yes <input type="checkbox"/> No
5(d) Where will the data be recorded?	<input checked="" type="checkbox"/> Manual forms <input type="checkbox"/> Other (please specify) <input type="checkbox"/> Electronic forms <input type="checkbox"/> Electronic spreadsheet		

	X Electronic database	
5(e) Where will it be stored?	X In a locked cabinet <input type="checkbox"/> Other (please specify) X In a locked office X On shared folder on SLaM network <input type="checkbox"/> On secure network outside SLaM	
5(f) Additional security arrangements	X Password protected <input type="checkbox"/> Other (please specify) X Encrypted X Login required	
5(g) Will the data be transferred outside SLaM	<input type="checkbox"/> Yes, in an anonymised format X No <input type="checkbox"/> Yes, with identifiers You must contact dataprotectionoffice@slam.nhs.uk to register any transfer of personal identifiable information in advance.	
	If yes, how Physically in person <input type="checkbox"/> Physically using a secure courier Physically using registered mail services <input type="checkbox"/> Electronically using nhs.net e-mail Electronically using encrypted portable media <input type="checkbox"/> Other (please specify)	
5(h) Will the data leave the EU?	<input type="checkbox"/> Yes (Please specify where and why) X No	
5(i) Information Asset Owner: This is the person responsible for the data	Name:	Dr Rhianna Watts
	Job title:	Clinical Psychologist
	CAG:	Child and Adolescent
	Organisation:	Forensic Psychology Service

(6)Data Collection (please answer ALL of the following questions)	
6(a) Where from? Audit data can be collected from many sources including: medical records/ePJS, nursing records, patients, clinicians, and other staff.	Referrer satisfaction questionnaires; Team database
6(b) How? The data source will obviously influence the method used to collect data. E.g. If data is to be collected from patients the most appropriate method might be a survey or interview. If data is to be collected from medical records, it will be necessary to design a data collection proforma. Questionnaires, one-to-one interview, focus groups.	Referrer satisfaction questionnaires
6 (c) How much? As a guide, a sample should include a minimum of 30 cases and perhaps as many as 100. If the initial sample proves to be too small to provide data necessary, it can be added later.	Approximately 40 cases
6 (d) Who? Who will be responsible for collecting the data? Ensure the person identified understands their role.	Dr Rhianna Watts and Miss Ukwuori-Gisela Kalu

6(e) Timescale? Over what period is the data to be collected?	November 2012 – November 2014
6 (f) Pilot Audit? Y/N In most cases it will be advisable to carry out a pilot to check quality of questionnaire, length of interview, etc. In light of the pilot audit findings, modifications to any of the above may need to be made.	Y
7(a) Who will be affected by the outcomes of this project? The service (the team); patients, their families and carers; referrers	
7(b) With whom and where will the final report be shared? i.e. Local Clinical Governance Committees, CAEC? The Service (team); CAMHS CAG; SLaM Audit; Institute of Psychiatry, and King's College London. Results may also be disseminated to a wider audience of professionals working with young people with offending behaviour and mental health difficulties, as part of national plans to improve services.	
7(c) Who will take responsibility for disseminating the results of the project and following through recommendations and actions? And how and when will the recommendations and actions be evaluated, monitored and reviewed? Dr Rhianna Watts and Miss Ukwuori-Gisela Kalu will be responsible for disseminating the results of the project and making recommendations to the team. Any recommendations will be evaluated/reviewed by the team after a period of 6 months. Any changes made as the result of the audit will be re-audited within 12 months in order to close the audit loop.	
All completed projects must be followed up with a completed audit recommendations monitoring form, available on the SLaM Clinical Audit & Effectiveness Intranet site http://sites.intranet.slam.nhs.uk/cg/default.aspx	
8) Audit Approval	
8(a) Information Governance Approval: IG Audit approval given by: Information Governance department Date Audit IG approved: 21.12.2012	8(b) Clinical Audit Ethical approval given by: Clinical Audit Ethical approval given by: CAMHS Audit Committee Date of Clinical Audit Committee approval: 21.12.2012 <input type="checkbox"/> Clinical Effectiveness and Audit Committee <input type="checkbox"/> Drugs and Therapeutics Committee <input checked="" type="checkbox"/> Directorate Clinical Governance/Audit Committee

Appendix 2: List of all standardized measures used by the service (prior to this service evaluation)

Assessments of Cognitive Functioning

- The Developmental NEuroPSYchological Assessment 2nd edition (NEPSY-II)
- The Behavioral Assessment of Dysexecutive Syndrome (BADS)
- The Hayling and Brixton Test
- The Wechsler Adult Intelligence Scale 4th edition (WAIS-IV)
- The Wechsler Abbreviated Scale of Intelligence 2nd edition (WASI-II)
- The Wechsler Individual Achievement Test 2nd edition (WIAT-II)
- The Wechsler Intelligence Scale for Children 4th edition (WISC-IV)
- The Wechsler Memory Scale 4th edition (WMS-IV)

Structured Risk Assessments

- The Estimate of Risk of Adolescent Sexual Offense Recidivism (ERASOR)
- The Structured Assessment of Violence Risk in Youth (SAVRY)

Assessment of Neurodevelopmental Disorders

ASD

- The Autism Diagnostic Observation Schedule – Generic (ADOS-G)
- The Autism Diagnostic Interview – Revised (ADI-R)
- The Diagnostic Inventory for Social Communication Disorder (DISCO) – self and informant rating
- The Social Communication Questionnaire (SCQ)

ADHD

- Connors Rating Scale – Revised or 3rd edition – informant rating

Behaviour Ratings Scales

- The Strength and Difficulties Questionnaire (SDQ) – informant rating
- The Behavioural Rating Inventory of executive Functioning – self and informant rating

Anger Rating Scales

- The Adolescent Anger Rating Scale (AARS)
- The NOVACO anger scale and provocation inventory (NAS-PI)

Depression / Anxiety Rating Scales

- Beck Youth Inventories
- Beck Depression inventory – youth & Beck Anxiety inventory – youth

Assessment of Legal Concerns

- The Gudjonsson Suggestibility Scale
- The Gudjonsson Compliance Scale

Other

- The Brief Psychiatric Rating Scale (BPRS-18)

Appendix 3: A brief summary of each national governance guideline reviewed within this service evaluation

- 1) *Community Forensic Child and Adolescent Mental Health Services (FCAMHS): a map of current national provision and a proposed service model for the future. Final Report for the Department of Health (Solutions for Public Health (SPH), 2013).*

This report addresses a series of questions in relation to community FCAMHS provision. The report is divided into three parts, and only part 3 – description of a validated service model and service standards for community FCAMHS – was considered for this review. The section suggests a range of validated measurement tools for monitoring progress and outcome of children and young people, which are recommended by the CAMHS Outcome Research Consortium (CORC; a collaboration between CAMHS services in the UK with the aim of instituting a common model for routine outcome evaluation and analyzing data derived). These include the Strengths and Difficulties Questionnaire (SDQ); the Commission for Health Improvement (CHI); the Experience of Service Questionnaire (ESQ); the Children's Global Assessment Scale (CGAS); the Health of the Nation Outcome Scale for Children and Adolescents (HoNOSCA); and the Goals Based Outcome Measure (GBO). However, the report advises that further appraisal of these should be considered in the light of the complex needs of the target population.

- 2) *The Forensic Mental Health Matrix – A guide to delivering evidenced based psychological therapies in forensic mental health services (National Education for Scotland, 2009).*

This guide makes recommendations about the most appropriate way to deliver forensic psychological therapy and it is intended for the application in both community and in-patient services. The guide states that all individuals require a comprehensive assessment of risk, needs and strengths that leads to a collaborative and shared formulation, which forms the basis for intervention planning. The guide further states that an assessment of the individual's level of risk should be carried out with all individuals at the time of entry to a service, and that this assessment should produce a detailed formulation to explain the problems, risks and needs presented and an

opinion on the nature and circumstances of possible re-offending. This should also include a risk management plan.

- 3) *The Health needs assessment of young people in London with complex emotional, behavioural and mental health problems who are or may be at risk of committing a serious crime (Health in Justice LLP, 2010).*

This needs assessment report states that London has a group of children and young people with complex emotional, behavioural and mental health problems who are or may be at risk of committing serious crimes; that these individuals are vulnerable, along with their families and the community within which they live; and that these individuals pose a problem that requires a multi-system response. The report identifies that the multi-system response relevant to the implementation of good practice should include the recognition that these individuals may need enhanced and tailored responses; taking full account of their individual vulnerabilities; properly address problems arising from experiences of discrimination; ensure proper attention is paid to safeguarding; establish a trusting relationship for each individual; encourage engagement of the individual and their families; and the long term availability of services. In addition, the report states that a pyramid of multi-disciplinary skills is necessary to manage the mental health problems of this population, and that these skills need to be available in a responsive (to chaos and crisis) and timely manner, as well as being gender sensitive.

- 4) *Practice standards for young people with substance misuse problems (College Centre for Quality Improvement; CCQI, 2012).*

These standards state that all staff in contact with young people aged eighteen or under should have the competences to identify those individuals at risk of (developing) a substance misuse problem; know when a more detailed assessment is required; and be either able to conduct the assessment, or quickly access an appropriate skilled professional to take the next steps. The standards specify that for all young people aged eighteen or under identification should simply involve brief questioning about substance misuse as per NICE clinical guidelines 51 (2008; see below). If concerns are identified for young people under the age of fifteen, the standards advise that a

comprehensive assessment of health, education, and social care needs (including substance misuse, mental health, physical health, family and other complexities) should be completed. Where concerns are identified for young people aged fifteen and over, the standards recommend a more detailed assessment of the young person's use and the appropriate offer of advice and/or intervention. The guidelines advise that a comprehensive assessment should include the following domains: substance misuse behaviour and related risk (including time-lines, supported by age-appropriate valid and reliable rating scales or structured interviews); development (including education and mental health, pre-morbid and/or comorbid psychiatric or behaviour disorders); physical health (including consideration of direct [e.g. abscess, hepatitis, bronchitis] and indirect impact on health [e.g. sexual health]; risk and safeguarding concerns; family history and functioning (both past and current with respect to the young person's relationships); resilience factors; and an interview of parent(s)/carer(s). The standards recommend the following substance misuse assessment instruments. For alcohol specifically, the Alcohol Use Disorder Identification Test (AUDIT-C; Knight et al, 2003) and the Single Alcohol Screening Questionnaire (SASQ) are recommended. For both drug and alcohol, the standards recommend CRAFFT (Knight et al, 1999); the SQIFA and the Maudsley Adolescent Substance Misuse Tool (MASQ).

5) *The Quality Network for Community CAMHS Service Standards, 3rd Edition (2011).*

These standards address all young people up to the age of eighteen, including those with learning disabilities and autistic spectrum disorders, or comorbid substance misuse problems. The third edition also include a subset of additional standards for young people with severe and complex mental health needs. The standards are arranged in sections, and for the scope of this project the 'Assessment and care planning section' only was considered. The standards recommend that young people receive timely assessments (i.e. within a maximum of 5 weeks for non-urgent assessments and within twenty-four hours or the next working day in emergency cases). In addition, the standards recommend that assessments are effectively coordinated with other agencies so that young people and their parent(s) or carer(s) are not repeatedly asked to give the same information. This includes identification of the involvement of other services; access to relevant previous information; and if

additional information or liaison is required, the insurance that permission to access this is sought first from the young person or their parent(s)/carer(s). The standards additionally recommend that the young person and their parent(s) or carer(s) are fully informed and involved in an assessment. This includes that clinicians check that the young person and their parent(s) or carer(s) understand the purpose of the assessment and possible outcomes as fully as possible before an assessment is conducted. This also includes that the young person's views, wishes and feelings are actively sought and recorded during the assessment, as far as this is possible with regard to capacity. In addition, this involves ensuring that the young person's, their parent(s) or carer(s) and/or the referrer(s) are provided with feedback on the outcome of the assessment, including explanation of the nature of the young person's problems and further recommendations. Finally, the standards recommend that assessments are individual and designed according to needs. This includes that an assessment report shows consideration of the young person's level of functioning and communication needs; the young person's family and community needs and context; the young person's abilities and strengths as well as their difficulties; in the case of concerns about possible alcohol or drug use, the assessment employs an age-appropriate valid assessment instrument for the extent of use and potential harm; and identification and evaluation of relevant risks.

In addition to the guidelines above, the following 14 NICE child mental health guidelines were identified and reviewed:

- 6) *NICE clinical guidelines 26 (2005). Post-traumatic stress disorder (PTSD). The management of PTSD in adults and children in primary and secondary care.*

These guidelines highlight that the identification of PTSD in children presents particular difficulties. However, these are improved by asking children directly about their experience. When assessing a child or young person for PTSD, professionals should therefore ensure that they separately and directly ask the child or young person about the presence of PTSD symptoms. The guidelines advise that an assessment should not solely rely on information from the parent or carer. In addition, children (particularly those under the age of 8 years) may not complain directly of PTSD symptoms such as

re-experiencing or avoidance. Instead children may complain of sleeping problems. In an assessment of PTSD in children, and particularly young children, consideration should therefore be given to ask the child and or the parents about sleep disturbances or significant changes to sleeping patterns. The guidelines further recommend that an assessment of PTSD should be comprehensive, including physical, psychological and social needs, as well as a risk assessment. Where language or cultural differences exist, the guidelines advise on the use of interpreters and bicultural professionals, and recommends that healthcare professionals familiarize themselves with the cultural background of their clients. The guidelines highlight that professionals should pay particular attention to the identification of individuals with PTSD where the culture of the working or living environment is resistant to recognition of the psychological consequences of trauma. No specific assessment tools (i.e. questionnaires or tests) are recommended within the guidelines.

7) *NICE clinical guidelines 28 (2015). Depression in children and young people: Identification and management in primary, community and secondary care.*

These guidelines cover the identification (and treatment) of depression in children between the ages of five and 11, and young people between the ages of 12 and 18. The guidelines state that in the assessment of depression in children and young people, special attention should be paid to the issue of confidentiality, the young person's consent, parental consent, child protection, the use of the Mental Health Act in young people, and the use of the Children Act. The form of assessment should also take account of cultural and ethnic variations in communication, family values and the place of the child or young person within the family. The guidelines highlight that family context, previous history of depression, and the degree of associated impairment are all important in helping to assess depression. It is therefore advised to assess how a child or young person functions in different settings (e.g. at school, with peers and with family). The guidelines further advise that when assessing a child or young person for depression, healthcare professional should routinely consider and record potential comorbidities, and the social, educational and family context for the patient and family members, including the quality of interpersonal relationships, both between the patient and other family members and with their friends and peers.

Further to this, the guidelines advise that in the assessment of a child or young person with depression, healthcare professionals should always ask the child or young person and their parent(s) or carer(s) directly about the child or young person's potential alcohol or drug use, any experiences of being bullied or abused, self-harm and ideas about suicide. In the case of a young person, he or she should be offered the opportunity to discuss these issues initially in private. When a child or young person has been diagnosed with depression, the guidelines state that consideration should be given to the possibility of parental depression, parental substance misuse, or other mental health problems and associated problems of living, as these are often associated with depression in a child or young person and, if untreated, may have a negative impact on the success of treatment offered to the child or young person. When a child or young person with depression is being monitored, the self-report Mood and Feelings Questionnaire (MFQ) should be considered as an adjunct to clinical judgment. Finally, the guidelines recommend that all healthcare and CAMHS professionals should routinely use and record appropriate outcome measures such as the Health and the National Outcome Scale for children and Adolescents (HoNOSCA) or the Strengths and Difficulties Questionnaire (SDQ).

8) *NICE clinical guidelines 51 (2007). Drug misuse. Psychological Interventions.*

These guidelines state that all staff in mental health and criminal justice settings should routinely ask service users about recent legal and illicit drug use. These questions should include whether individuals have used drugs and if so; the type and nature of administration; the quantity; and the frequency of use. In addition, when conducting an assessment, staff should consider the service user's: medical, psychological, social and occupational needs; the history of drug use; the experience of previous treatment for drug use (if any); goals and motivations in relation to drug use; and drug treatment preferences.

9) *NICE clinical practice guideline 52 (2008). Drug misuse: Opioid detoxification.*

These guidelines are, in most, specific to people presenting for opioid detoxification. However, it is highlighted that many people who misuse drugs do not present to drug treatment services, with approximately 50% not seeking treatment. Due to the high

prevalence rate of drug use, the guidelines advise that all healthcare professionals should be able to identify and carry out a basic assessment of people who use drugs. The guidelines state that a good assessment includes information about past and current drug use (i.e. amount, type, duration, periods of abstinence and effects of abstinence), history of injecting, risk of HIV and other blood-borne viruses, medical history, forensics and previous contact with treatment services. In addition, the guidelines highlight that immediate advice on harm minimization (including access to sterile needles and syringes where this is appropriate, as well as testing for HIV and hepatitis, and immunization against hepatitis) should be provided.

10) NICE clinical guideline 72 (2008). Attention deficit hyperactivity disorder (ADHD).

Diagnosis and management of ADHD in children, young people and adults.

These guidelines advise that care is required in differential diagnosis of ADHD, as common coexisting condition in children with ADHD are disorders of mood, conduct, learning, motor control and communication. The guidelines further advise that a diagnosis should only be made by an appropriately qualified healthcare professional on the basis of a full clinical and psychological assessment of the person (including a discussion about the behaviour and symptoms in the different domains and settings of the person's everyday life), a full developmental and psychiatric history, and observer reports and assessments of the person's mental state. Two rating scales are recommended; the Conner's rating scales and the Strengths and Difficulties scales. The guidelines further advise that the diagnostic process should include an assessment of the person's needs, coexisting conditions, social, familial and educational or occupational circumstances and physical health. For children and young people this should also include an assessment of their parent's or carer's mental health. Lastly, the guidelines advise that determination of the severity of the disorder should be a matter for clinical judgment, taking into account the level of impairment, pervasiveness, individual factors and family and social context. The level of severity can alternatively be estimated using a predetermined level on a global adjustment scale, such as the children's global assessment scale (C-GAS).

11) NICE clinical guidelines 77 (2009). Antisocial personality disorder. Treatment, management and prevention.

These guidelines advise that under current diagnostic systems, antisocial personality disorder is not formally diagnosed before the age of 18 years, but the features of the disorder can manifest earlier as conduct disorder and a history of conduct disorder before the age of 15 years is a requirement for a diagnosis of antisocial personality disorder in the DSM-IV. The guidelines further state that antisocial personality disorder is often comorbid with depression, anxiety and alcohol and drug misuse. The guidelines advise that healthcare professionals in forensic services should routinely use a measure of the severity of antisocial personality disorder such as the Psychopathy Checklist-Revised (PCL-R: YV), as well as a risk assessment tool such as the SAVRY or ERASOR.

12) NICE clinical guidelines 78 (2009). Borderline personality disorder: treatment and management.

These guidelines advise that borderline personality disorder is often comorbid with depression, anxiety, eating disorders, post-traumatic stress disorder, alcohol and drug misuse, and bipolar disorder. Assessing a person with possible borderline personality disorder should include psychological and occupational functioning, coping strategies, strengths and vulnerabilities, and comorbid mental disorders and social problems. The guidelines further advise that a risk assessment should take place as part of a full assessment of the needs of a person with borderline personality disorder (although no specific risk assessment measure is mentioned). This risk assessment should also differentiate between long-term and more immediate risks, and identify risks posed to self and others (including dependent children).

13) NICE clinical guidelines 115 (2011). Alcohol-use disorders: Diagnosis, assessment and management of harmful drinking and alcohol dependence.

These guidelines make recommendation on the diagnosis, assessment and management of harmful drinking and alcohol dependence in adults and in young people aged 10-17 years. The guidelines recommend the use of the following formal assessment tools to assess the nature and severity of alcohol misuse. These include the

Alcohol Use Disorder Identification Test (AUDIT) for identification and as a routine outcome measure, the Severity of Alcohol Dependency Questionnaire (SADQ) or the Leeds Dependence Questionnaire (LDQ) for severity of dependency, the Clinical Institute Withdrawal Assessment of Alcohol Scale revised (CIWA-Ar) for severity of withdrawal, and the Alcohol Problems Questionnaire (APQ) for the nature and extent of the problems arising from alcohol misuse. The guidelines further advise that a comprehensive assessment should also address other drug misuse (including over the counter medication) and cognitive functioning (e.g. as per Mini-Mental State Examination; MMSE). The Adolescent Diagnostic Interview (ADI) or the Teen Addiction Severity Index (TASI) are recommended for the assessment of children and young people.

14) NICE clinical guidelines 120 (2011). Psychosis with coexisting substance misuse. Assessment and management in adults and young people.

These guidelines cover the assessment (and management) of adults and young people (aged 14 years and older) who have a clinical diagnosis of psychosis with coexisting substance misuse. Within the guidelines, substance misuse encompasses the harmful use of any psychotropic substance (including alcohol and either legal or illicit drugs). The guidelines recommend that all health care professionals should routinely ask adults and young people with known or suspected psychosis about their use of alcohol and/or prescribed and non-prescribed (including illicit) drugs. If the individual has used substances, professionals are advised to inquire about the nature, quantity, frequency, pattern, route of administration, duration and level of use. The guidelines additionally recommend an assessment of dependency (see under NICE 52 and 115) for these individuals, as well as corroborative evidence from families, carers and significant others where this is possible and permission has been given. Similarly, the guidelines recommend that all healthcare professionals should routinely assess adults and young people with known or suspected substance misuse for possible psychosis, and seek corroborative evidence from families, carers and significant others where this is possible and permission has been given. The guidelines state that adults and young people with psychosis and coexisting substance misuse attending mental health services should be offered a comprehensive, multidisciplinary assessment, including all

of the following areas: personal history; mental, physical and sexual history; social, family and economic situation; accommodation, including history of homelessness and stability of current living arrangements; current and past substance misuse and its impact upon their life, health and response to treatment; criminal justice history and current status; and personal strengths and weaknesses and readiness to change their substance use and other aspects of their lives. The guidelines mention that this assessment may need to take place over several meetings to gain a full understanding of the person and the range of problems they experience, and to promote engagement. Finally, the guidelines recommend the assessment of risk of harm to self and/or others and the development and implementation of a risk management plan, which specifically considers risks associated with substance misuse. These include physical health risks (e.g. withdrawal seizures, delirium tremens, blood-borne viruses, accidental overdose, and interactions with prescribed medications), and the impact the substance misuse may have on other risks such as self-harm, suicide, self-neglect, violence, abuse of or by others, exploitation, accidental injury and offending behavior.

15) NICE clinical guidelines 128 (2011). Autism diagnosis in children and young people. Recognition, referral and diagnosis of children and young people on the autism spectrum.

These guidelines cover the recognition, referral and diagnosis of autism in children and young people from birth up to 19 years. The guidelines highlight the importance of coordination between health agencies and other key services such as education, social care and the voluntary sector. The guidelines advise that an autism diagnostic assessment should be started within 3 months of referral and that one person (i.e. case coordinator) within the team should be identified to act as a single point of contact for the parents or carers through whom they can communicate with the rest of the team. The guidelines recommend that every autism diagnostic assessment includes detailed questions about parent's or carer's concerns, as well as (if appropriate) the child's or young person's own concerns. In addition, the guidelines recommend that the diagnostic assessment should include details of the child's or young person's experience of home life, education and social care; a developmental history (focusing on developmental and behavioural features consistent with an ICD-10 or DSM-V

criteria); an assessment of social skills and behaviour through interaction with and observation of the child or young person (focusing on features consistent with ICD-10 or DSM-V); a medical history that includes prenatal, perinatal and family history, as well as past and current health conditions; a physical examination (specifically looking out for e.g. signs of injury such as self-harm or child maltreatment); a systematic assessment for coexisting conditions; and the development of a profile of the child's or young person's strength, skills, impairments and needs that can be used to create a needs-based management plan. For this profile, the guidelines recommend the consideration of specific assessments, such as intellectual ability, academic skills, speech and language, fine and gross motor skills, adaptive behaviour, mental and emotional health, physical health and nutrition, sensory sensitivities, and social skills. The guidelines advise further that a diagnostic assessment should consider the following differential diagnose and whether specific assessments are needed to help interpret the autism history and observations. These include, neurodevelopmental disorders (such as specific language delay or disorder, intellectual disability or global developmental delay, and developmental coordination disorder (DCD)), mental and behavioural disorders (such as ADHD, mood disorders, anxiety disorders, attachment disorders, conduct disorder, OCD and psychosis), conditions in which there is developmental regression (such as rett syndrome and epileptic encephalopathy), and other conditions (such as severe hearing impairment, severe visual impairment, maltreatment and selective mutism). To help identify the signs and symptoms of possible autism three tables are presented as guidance, but it is highlighted that these do not include all possible manifestations of autism. The guidelines also highlight that particular considerations are needed in cases such as, for example, looked-after children, those in the criminal justice system and older teenagers, where information about early development may not readily available. Where discrepancies between reported signs or symptoms and the findings of an assessment are detected, the guidelines advise the gathering of further information through observation in different settings (e.g. school, social setting or at home). No specific assessment tools (i.e. questionnaires or tests) are mentioned within these guidelines.

16) NICE clinical guidelines 133 (2011). Self-harm: long-term management.

These guidelines are addressed to all health and social care professionals who come into contact with individuals aged 8 years and older who self-harm. The guidelines advise an integrative and comprehensive psychosocial assessment of needs and risks to understand and engage individuals who self-harm. Interestingly, the guidelines strongly discourage the use of risk assessment tools and scales to predict future self-harm.

17) NICE clinical guidelines 155 (2013). Psychosis and schizophrenia in children and young people. Recognition and management.

These guidelines are concerned with the recognition (and management) of psychosis and schizophrenia in children and young people up to the age of 18 years. Within the guidelines the term 'psychosis' refers to the group of psychotic disorders that include schizophrenia, schizoaffective disorders, schizophreniform disorder and delusional disorder. The guidelines also address those children and young people considered clinically to be at high risk or prodromal of psychosis and schizophrenia. The guidelines recommend that all health and social care professionals should ensure that they are able to assess capacity and competence, including 'Gillick competence', in children and young people of all ages, and understand how to apply legislation (including the Children Act 1989, 2004; the Mental Health Act 1983, 1995, 2007; and the Mental Capacity Act 2005) in the care of children and young people. The guidelines further advise that all health and social care professionals consider children and young people with psychosis or schizophrenia for assessment according to local safeguarding procedures if there are concerns regarding exploitation or self-care, or if they have been in contact with the criminal justice system. In regard to culture and ethnicity, the guidelines highlight that professionals should be aware of possible variation in the presentation of mental health problems in children and young people of different genders, ages, cultural, ethnic, religious or other diverse backgrounds. Particularly, professionals should 1) provide or work proficiently with interpreters if needed, 2) be competent in assessing people from diverse ethnic and cultural backgrounds, 3) address cultural and ethnic differences in beliefs regarding biological, social and family influences on the possible causes of mental health problems, and 4) seek advice and

supervision from professionals who are experienced in working transculturally. When carrying out an assessment of a child or young person with possible psychosis, the guidelines recommend that a consultant psychiatrist is included in this process. In particular, the guidelines state that an assessment by a consultant psychiatrist with training in child and adolescent mental health is required where uncertainty about a diagnosis or concerns about underlying neurological illness exist. The assessment itself should allow for enough time for the child or young person (and their parents or carers) to explain and discuss their problems, and to offer support after the assessment when sensitive issues such as childhood trauma have been discussed. Further to this, the guidelines state that an assessment should address the following domains: psychiatric (i.e. mental health problems, risk of harm to self or others, alcohol consumption and history of prescribed and non-prescribed drug use); medical (including a full physical examination); psychological and psychosocial (i.e. social networks, relationships and history of trauma); developmental (i.e. social, cognitive and motor skills development); physical health and wellbeing (i.e. weight and height; information about smoking, diet, exercise and sexual health); social (i.e. accommodation, culture, ethnicity, leisure activities, carer responsibilities of parents or siblings); educational and occupational (i.e. attendance at school or college, educational attainment, and employment and functional activity); and economic (i.e. family's economic status). The guidelines also advise that the assessment should address possible coexisting mental health problems such as depression, anxiety and substance misuse. The guidelines do not recommend any specific measures or questionnaires for the assessment.

18) Psychosis and schizophrenia in children and young people. The NICE guidelines on recognition and management. National Collaboration for Mental Health (BPS & Royal College of Psychiatrist, 2013).

These guidelines are more comprehensive and detailed than the NICE guidelines 155 (see above). The assessment of children and young people with psychosis or schizophrenia is divided into pre-pubertal children and young people. For the assessment of pre-pubertal children the guidelines highlight that the prevalence of psychosis and schizophrenia is very low, and that diagnosis is largely based on the

effective communication by the child to others of a mixture of unusual subjective mental experiences, poor integration of sensory, emotional and cognitive experiences and bizarre behaviour. The guidelines describe that young children's ability to integrate and communicate these experiences develops gradually before puberty, thus making a diagnosis more difficult than in young people and adults, and more likely based on behaviour than subjective experiences. The guidelines highlight that the majority of children display pre-morbid psychiatric disturbances, most commonly ADHD, conduct problems (with aggression, truancy and fire setting) and developmental abnormalities within the autistic spectrum (present 25%). In the actual assessment process, the guidelines recommend the inclusion of mental state, physical examination (including detailed physical examination, blood tests, MRI scanning for more complex presentations, EEG if seizures are suspected, and possibly genetic testing) and a detailed developmental history, paying particular attention to pre-morbid functioning. As the child's cognitive level will influence their ability to both express and understand complex psychotic symptoms and subjective experiences like hallucinations, an assessment of cognitive functioning (i.e. psychometric baseline) and an assessment of speech and language problems are also recommended. The guidelines further highlight that engagement with the child and gaining their confidence may require a number of sessions. For the assessment of young people the guidelines advise on the need for flexibility and adaptation to the young person's age and developmental level in terms of setting, language and style of interviewing. Empathetic and curious enquiry regarding the young person's current life situations, concerns and predicaments are recommended as starting point to the assessment. This will then need to progress to a more comprehensive assessment of the young person's global functioning and developmental history. The guidelines advise further that the assessment should encompass careful enquiry about core symptomatology, particularly of abnormal belief system, perception, thoughts and experiences. Physical health should also be considered (as in pre-pubertal children). However, the role of substance use as both causative and a comorbid or exacerbating factor requires further careful exploration in this age group. Similarly, the guidelines advise particularly for this age group that risk both to self and others need to be assessed and placed carefully within the developmental stage of adolescence (where a degree of risk

taking is both normal and necessary for individuation). Lastly, for both age groups the guidelines advise on the importance on collateral information for parents or carers and schools. No specific assessment measures or questionnaires are recommended, but the use of semi-structured interview tools as adjunct to the clinical interview are mentioned.

19) NICE clinical guidelines 158 (2013). Antisocial behaviour and conduct disorder in children and young people: recognition, intervention and management.

These guidelines recommend the use of the Strength and Difficulties Questionnaire (SDQ) in the initial assessment of a child or young person with suspected conduct disorder. Assessment for the presence of significant complicating factors using relevant formal assessment measures is also advised. These include, coexisting mental health problems such as depression and PTSD, neurodevelopmental disorders such as ADHD and autism, a learning disability or difficulty, and substance misuse. The guidelines further advice that a comprehensive assessment should include the core conduct disorder features, current functioning at home in school and with peers, parenting qualities, histories of past and present physical and mental health.

Appendix 4: The newly developed compulsory assessment package

Assessment Parts:

1. Background Information and Liaison with other services/professionals
2. Clinical Interview with young person
3. Clinical Interview parent(s), carer(s) and or other(s)
4. Observation - multi-setting: assessment, school/college, home, peers
5. Feedback session
 - a. With referrer
 - b. With young person and or parent(s), carer(s)/ other(s)

Assessment Domains and Measures:

➤ Use the SDQ with all young people and or parent(s)/ Carer(s)/ other(s)*

- I. Psychiatric
 - Mental health (including comorbidities)
 - For Depression and Anxiety : Beck Youth Inventory; MFQ
 - For antisocial personality disorder: PPCL-R:YV
 - Alcohol and Substance misuse
 - For Alcohol: AUDIT-C; the LDQ if positive screen
 - For Alcohol and Drugs: CRAFFT
- II. Psychological & Psychosocial
 - Cognitive functioning
 - WAIS-IV; WASI-II; NEPSY-II; WIAT-II; WMS-IV; WISC-IV; BADS; Hayling & Brixton etc.)
 - Forensic history & risk (to self & others)
 - For a Structured Risk Assessment: SAVRY; ERASOR
 - For Anger and Aggression: AARS, NOVACO
 - For Legal Concerns: Gudjonsson Suggestibility Scale; Gudjonsson Compliance Scale
 - Family functioning and parenting
 - The PS
 - History of trauma, bullying and discrimination
- III. Social
 - Social networks and relationships
 - The MSPSS
 - Accommodation
 - Culture and ethnicity
 - Carer responsibilities/safeguarding
 - Exercise and leisure activities
- IV. Developmental
 - Social, cognitive and motor development
 - For ADHD: the Conner's rating scale
 - For ADS: ADOS-G; ADI-R; DISCO; SCQ
- V. Educational and or Occupational
 - Attendance at school/college
 - Educational attainment
 - Employment or functional activities
- VI. Needs and Strengths (including goals)

Red = indicates *required* parts, domains and measures (as identified through the review of national guidelines)

Orange = indicates *desirable* parts, domains and measures

Blue = indicates optional measures (to be used where indicated by referral or individual's need)

Appendix 5: The service specific referral satisfaction questionnaire

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PERSONAL DETAILS (VOLUNTARY)

Name: Date:

Profession:

Work address:

ACCESS TO OUR SERVICE

How frequently do you **refer** to our services?

☐ Very frequently ☐ Frequently ☐ Occasionally ☐ Once ☐ Never

In general, how frequently do you **have contact** with professionals from our service?

☐ Very frequently ☐ Frequently ☐ Occasionally ☐ Once ☐ Never

Please indicate **which means of communication** you most frequently use to contact professionals from our service: (please tick one box only)

☐ None ☐ Phone ☐ Letter ☐ Face-to-face ☐ Other (specify)

.....
.....

How easy do you feel it is to **access** professionals from our service when you wish to discuss or refer an individual?

☐ Very easy ☐ Easy ☐ Difficult ☐ Very difficult

QUALITY OF OUR SERVICE

If you have referred to our service more than once, please answer the following questions in relation to the most recent referral.

How satisfied are you with the **initial information** provided by our service?

☐ Very satisfied ☐ Satisfied ☐ Dissatisfied ☐ Very dissatisfied

How satisfied are you with the **referral procedure** to our service?

☐ Very satisfied ☐ Satisfied ☐ Dissatisfied ☐ Very dissatisfied

How satisfied are you with the **assessment waiting time**, e.g. the time between referral and the individual being seen?

☐ Very satisfied ☐ Satisfied ☐ Dissatisfied ☐ Very dissatisfied

How satisfied are you with the **report waiting time**, e.g. the time between the individual being seen and a report being provided by our service?

☐ Very satisfied ☐ Satisfied ☐ Dissatisfied ☐ Very dissatisfied

How satisfied are you with the **report** you received from our service about the individual you referred?

☐ Very satisfied ☐ Satisfied ☐ Dissatisfied ☐ Very dissatisfied ☐ Comments:

.....
.....
.....

Please indicate any **other type of feedback** you received from our service about the individual you referred:

☐ None ☐ Verbal feedback (e.g. over phone) ☐ Feedback session ☐ Other (specify)

.....
.....
.....

How useful was this **additional feedback** you received from our service about the individual referred?

☐ Very useful ☐ Useful ☐ Quite Useful ☐ Not at all useful

Please indicate the **main reason for referral** to our service for the individual referred (please tick one box only):

☐ Forensic risk assessment ☐ Cognitive / Intellectual assessment ☐ Intervention guidance ☐ Other (specify)

.....
.....
.....

Please indicate any **additional reasons for referral** to our service for the individual referred (please tick all applicable boxes):

☐ Forensic risk assessment ☐ Cognitive / Intellectual assessment ☐ Intervention guidance ☐ Other (specify)

.....
.....
.....

How well does the **assessment** offered by our service address your referral question?

☐ Very well ☐ Well ☐ Quite well ☐ Not at all

Has the input of our service been **beneficial to the individual** you referred to us?

☐ Definitely yes ☐ Probably yes ☐ Don't know ☐ Probably not ☐ Definitely not

Would you **refer to our service again**?

☐ Definitely yes ☐ Probably yes ☐ Don't know ☐ Probably not ☐ Definitely not

Do you have any (other) **suggestions** for the improvement of our service?

.....

.....

.....

.....

YOUR WORKING RELATIONSHIP WITH OUR SERVICE

Overall, how **well supported do you feel** by our service?

☐ Very well ☐ Well ☐ Poorly ☐ Very poorly

How well does our service currently **meet the needs of individuals** you referred to us?

☐ Very well ☐ Well ☐ Poorly ☐ Very poorly

How useful has our service been in **enabling you to become more knowledgeable** about emotional and behavioural problems of young individuals at risk of offending you refer?

☐ Very useful ☐ Useful ☐ Quite Useful ☐ Not at all useful

ANY ADDITIONAL COMMENTS

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.....

.....

.....

THANK YOU FOR HAVING COMPLETED THIS QUESTIONNAIRE

Appendix 6: Cover letter for referral satisfaction



FORENSIC PSYCHOLOGY SERVICE
National and Specialist CAMHS
Michael Rutter Centre for Children and Young People
The Maudsley Hospital
De Crespigny Park
Denmark Hill
London SE5 8AZ

Tel: 020-3228 274

Fax: 020-3228 501

Dear ...,

You are receiving this letter because you have recently/in the past referred to the Child and Adolescent Forensic Psychology Service.

The Child and Adolescent Forensic Psychology Service is a relatively new National and Specialist CAMHS assessment and intervention service, and as such we are currently in the process of evaluating our service. This evaluation is conducted on behalf of the service by a Clinical Psychologist Trainee, as part of her training at the Institute of Psychiatry.

Enclosed is a questionnaire, which will help us assess the level of referrer satisfaction with our service. We would be very grateful if you could take a few minutes to complete this questionnaire and then return it to us in the enclosed envelop. However, please note that you are under no obligation to do so, and completion will not affect the service we provide to you and/or the individuals you refer to our service.

Please also be advised that everything you tell us on the questionnaire (both in regard to you and the individual you referred to us) will remain completely confidential. You are under no obligation to provide any personal and/or contact information. The information that you give us on the questionnaire will be *completely anonymised* and linked only to a numerical ID. You are free to withdraw your questionnaire at any point in time before March 2013.

A member of our team will contact you within the next two weeks to confirm that you have received this letter and at this point will also be able to answer any further questions you may have.

Thank you very much for your help.

Kind regards,

The Child and Adolescent Forensic Psychology Service